

Daisy - a journey towards accepting and loving a child with a disability.

Prologue

Let me not to the marriage of true minds
 Admit impediments. Love is not love
 Which alters when it alteration finds,
 Or bends with the remover to remove:
 O, no! it is an ever fixed mark,
 That looks on tempests and is never shaken;
 It is the star to every wandering bark,
 Whose worth's unknown, although his height be taken.
 Love's not Time's fool, though rosy lips and cheeks
 Within his bending sickle's compass come;
 Love alters not with his brief hours and weeks,
 But bears it out even to the edge of doom.
 If this be error and upon me proved,
 I never writ, or no man ever loved.

W Shakespeare
 Sonnet 116

Chapter 1

I am running down endless faceless corridors, my feet pounding on the polished floors. I push doors open in front of me and pant up stairwells taking 2, 3 steps at a time. More corridors with their echoing starkness. All the while screaming in my ears is the relentless piercing cry of an infant. I know the crying infant is mine and I cannot reach her, cannot provide for her, and cannot make the source of her distress go away. Running towards her with all my effort, all my strength and endeavour, but never arriving..

In the days before Daisy's birth I feel hopeful, confident and expectant in every sense of the word. The child, probably the first of many, will be intelligent, creative and musical. He will be gregarious and fun loving. The pregnancy is unexpected but, in the final year of my degree, I feel invincible; that anything is within my grasp. On track for a first, having a baby will only serve to expand my horizons, not constrict them. I can be an outstanding mother as well as an outstanding student and teacher. Bring it on! I can take it all in my stride.

I do all the right things in my pregnancy; swimming two or three times a week and long walks in the spring sunshine. I read an article in the Sunday papers about playing relaxing music to the unborn child. The intelligent child will respond to the rhythm of the music by slowing its own heartbeat in response to the mother's

relaxation. Whenever the opportunity arises, I lie on top of the patchwork quilt and let Faure's Requiem rest over me and soak into my soul.

At around 5 months into the pregnancy Peter and I go on holiday to the South of France. I feel the oxytocin – the “mothering hormone” flowing around my body, and am constantly amazed and delighted by the movements of the baby, gently turning over and growing; a new world within me. The area we are staying in has beautiful sandy beaches, warm, clear blue seas and I swim out to a rock where I sit and rest. I look back to the beach where people I saw yesterday, and the day before, carry out their holiday rituals; some have tidy and orderly areas of the beach, with well thought-out picnics and games neatly packed in bags; others are more chaotic in their holiday-making; towels scruffily arranged and covered in sand, snapping and snarling at their children and sniping at each other. I pick out Peter on the beach, content, alone, lying on his side, reading the Pickwick Papers, oblivious to all around him. Just a few short weeks and we too will have joined the fraternity of parents. Holidays will be so much more fun; cricket on the beach, swimming and laughing... not long to wait.

I return to the beach and sit and watch a slender lady, bronzed by her outdoor life. She wears a white peaked cap with her hair tucked inside. She is obviously well known by the locals and holidaymakers alike who exchange cheery “bonjour”s as she walks along the beach. Unbidden, children barely old enough to be walking, line up along the shoreline. She takes them one by one into the warm, shallow waters, and teaches them to swim before my very eyes, working by building their confidence in the water, most swim unaided within 15 minutes! “Look at that!” I say turning to Peter, “that is the way to teach; build confidence and make it fun. We will teach our child to swim like that, in the sea”

As I was speaking, the sky grew suddenly dark and the rain came thundering down. All around us, people hurriedly packed their books into their beach bags and ran into the sea. Perversely, one felt drier and warmer in the sea than on land. The sun peeped out and the summer storm passed as quickly as it had arrived. Gradually people began to swim back to shore and made their way back up the beach to their “rented” spot. The incident was soon forgotten but its drama seemed somehow significant to me.

The next day is as hot as ever. It is mid-June, the summer solstice, in the early evening we drive out of the town up a winding track to a medieval village. It is an idyllic evening and as we wander around the tranquil streets with their ancient stone cobbles and mellow, creamy stone buildings, it really seems that things can get no better for us; we have everything we could possibly want, and a wonderful new chapter beginning only just ahead of us. Peter looks out from the ramparts as I wander into the tiny church. It is much cooler in here. The walls are washed white and the blue and green stained-glass windows are exquisite in their simplicity. I slide onto a polished pew and gaze around me. The flickering candles on the altar, the beautiful simple architecture and the subdued sunlight from the windows. Often in such circumstances I feel close to God, not usually in spoken prayer, but just in a quiet closeness, like that of old friends. I anticipate the feeling and wait for itnothing. I stay a little longer and try to decipher one or two notices at the back of the church. I look around again at the quiet beauty of the place, and quietly close the door behind me.

As evening approaches we spot a promising-looking restaurant in the centre of the village. The door surrounded by the ubiquitous tubs and baskets of red ivy-leaved geraniums. We are shown to a table upstairs on the terrace over-looking fields upon fields of vineyards, with grapes hanging in abundance. In the distance is the cote d'azure. Fitting with the whole tenor of the evening, the meal is perfect. When it is over we ask the waitress to take a photograph of the two of us together.

In the years that follow I look at that photograph often. Now in a frame sitting on the bookcase, the photograph represents many things to me; it represents the end of something that was lovely, it represents the innocent unawareness of a terrible time that was coming; waiting at the door. Like the faces of the young boys who stare out trustingly from photographs taken in the years just preceding the First World War, We had no way of knowing what was to come. I feel something akin to yearning guilt as I take the photograph off the shelf to dust the frame. I want to warn you, to somehow prepare you, to reach out to you, poor children, how ill equipped you are to deal with what is to come. How young you look. How full of confidence and hope. Within a few short months a tidal wave will ruthlessly come crashing over you and leave you clinging to rocks for your dear life, and the life of your child, the life of your marriage, your very life itself, and it will leave you clinging there for years. Everything you know now will be washed away in that storm and you will have to rebuild your lives again out of the wreckage.

Back home again, a seed is takes root in my mind that all is not well. I have the inexplicable feeling that something is amiss with the baby. The feeling is so nebulous that I do not acknowledge it to anyone, not even to myself as a possible reality; I don't feel unwell. Quite the opposite, in fact; I feel better physically than I have ever felt. I feel positive and happy, but still...still..something. The strains of Faure's requiem haunt me with their beauty. Libera Me...

Some friends have just returned from holiday with another couple, also known to me. Drinking tea at her kitchen table she tells me about her time away. She tells me about an incident which happened one day on the beach, when their peace was apparently shattered by a group of young adults with Down's syndrome laughing and playing nearby. She had been angered and upset because her friend had complained to her about this; "they shouldn't let people like that come into public places where people are on holiday" I feel shocked and saddened by this story; sad for the young adults playing on the beach, because they would never be fully accepted whilst ever attitudes like this are still held and expressed, sad also because my own friend could call a person with such an attitude a friend of her own, sad because I feel tainted by the association, sad because of some other, deeper, more fundamental reason, not yet fully known.

The summer has been a hot one; and as August merges into September, the weather feels sultry. There is a feeling of rocking on a cusp; as if the whole of nature around me is waiting and waiting...something almost tangible in the air. One hot, still day I feel restless and walk across the woods and fields to my mother-in-law's house. We sit chatting and Peter calls on his way home from work. As the evening wears on I feel that something is happening. The baby is coming.

Chapter 2

Our journey to the hospital in our little white car with my two hurriedly packed bags is like a dream. It is the witching hour of the night when surreal things can happen, when commonplace things can take on a greater significance; if the lights are green it will be a boy, if the next car we see is a taxi I will have an easy labour. Too superstitious, I suppose, to make any bargains with any unseen forces at this hour of the night about whether “things would be alright.... or not...” The night air feels cool after such a hot day. All the street lights shine out ahead of us as if blazing a trail, heralding the new life that would be ours – so soon would be ours.

How innocently and quietly we go, walking straight into the trap.

Twelve hours later, a small, pink, silent form is wrenched from the ruins of my flesh. The baby is whisked away and given hurried, hushed attention by a crowd of doctors at the end of the room but out of my sight. The crowd of gowned medics form a wall of white backs as they pen my baby in the corner and claim to be clearing her airway with a tube. I am ashamed to say I am so utterly exhausted and shocked by the experience of labour and birth that I care not whether I hear the cry all good and normal mothers are supposed to long to hear, but hear it I eventually do. Three or four minutes later the group disband and I am presented with a crumple-faced, crying creature wrapped in a municipal orange towel.

In the days, months and years that follow I go over and over the story of what happened in that time, when days and nights blend into one. There is an ancient myth that, before they became the sanitised, pink-wearing goody-goodies we now know, fairies could be malevolent as well as benevolent, in certain circumstances. At significant times in nature, such as solstices or eclipses or full moons, wicked fairies, craving healthy human children, could and would swap their own offspring for newborn infants. The “changeling” left in the human child’s place would always be sickly, and never settle fully into the world of mortals and would be characterised by some distinguishing feature, such as a disability. This seemed to me an intriguing, almost compelling story as, in the time that follows I abandon any trust in God I previously had, and begin to make bargains and deals with – whoever might be listening or available to make a bargain with – God? Fate? Nature? Fairies? The devil? Everything I felt I knew and understood disappears from under my feet. There is a saying that when a person doesn’t believe in God, they don’t believe in nothing, they believe in anything

What of the plans we make for our lives when we are so powerless to influence even the smallest detail.”Put forth thine hand now and touch all that she hath, and she will curse thee to thy face...”

The nightmare truly begins, although at the time unknown to me, when a friendly nurse, Bridget, takes my baby in her arms and looks intently into her face. It is two hours or so after the birth and I am arranging and rearranging my belongings in the hospital locker whilst Bridget sits on a chair beside me. “Has she fed yet?” she asks me, not taking her eyes off the baby’s face. “Not really” I reply. “She doesn’t seem that interested, I expect she is tired after the birth. I will try again a bit later” Bridget continues to look into the tiny, sleepy face, which is now turning an alarming shade of

purple before our very eyes. She is obviously concerned and wondering about something, although she says nothing. A few minutes earlier I had seen Dr Dodds, the Consultant Paediatrician, standing at the nurses station. I have no acquaintance with him as I worked at the hospital as a medical secretary before I began my degree three years earlier. "The Consultant on call is just about to leave, I just want to catch him before he does" says Bridget carefully "do you mind if I take your baby with me" "No not at all" I say, still not thinking anything of it, I suppose I conceitedly think she just wants to show my baby off.

Was that when it happened? Did the dark-haired, dark eyed, Celtic Bridget arrange the swap then, I later wonder? Did Bridget have a pact with a malevolent spirit? She was gone for some time..... My baby in exchange for her own soul, perhaps?

Dr Dodds comes and sits by my bed. He looks kind. I still don't guess. "We would like to take your baby up to Special Care. It's really nothing to worry about but we want to check her blood sugar. We will have to get the cot ready so you still have time for a cuddle before we take her" I don't like the words "before we take her" I feel my smile freeze on my face. He sees it and reassures me. "Really" he says, "it's nothing to worry about"

He strides off down the ward and disappears through the swing doors. A few minutes later two fresh-faced, white-coated Senior House Officers appear at the foot of my bed. They look vaguely familiar. "Congratulations!" they gush. "How is it going?" they don't wait for an answer " You did really well in there" Then I remember seeing them through my entonox-induced haze in the delivery room. I smile and look down at my purple-faced bundle wrapped in her standard-issue hospital orange towel. "We were wondering, er, Rachel" hesitates the most vocal of the pair, glancing at the name above my bed, could we take your baby for just a couple of minutes to, er, check her blood sugar?" I should have known, did know, I suppose on one level, that this was totally out of order, and confirm my suspicions when I surreptitiously sneak a look at the hospital notes years later that what these inexperienced doctors were actually doing was playing "show and tell" with my baby, my beautiful baby, with their colleagues, discussing whether others thought she was "slightly odd looking", as they apparently thought. When I read these words later, they feel like a spear piercing my heart. Beginning to feel a bit bemused, I smile and agree. Amazingly though, I still didn't smell a rat. A few minutes later, the two junior doctors return with my baby. They both look a bit sheepish, I think, as they carefully hand her back to me. All I can think at the time, though, is the story which has recently been on the news about a baby who was kidnapped from a hospital ward in the South of England; a new mother trustingly handed over her baby to a man purporting to be a nurse and the baby was found days later in a house miles away, thankfully unharmed. How stupid I was to hand my own baby over so readily, and how relieved to have her back. But did I have my own baby back? It would have been simple for them to swap her then.....

Still feeling huge relief that the birth is now behind me and experiencing a bit of a carnival atmosphere, receiving a stream of visitors, all laughing and crying and bearing gifts, I laugh and joke with the nurse and the porter who come to wheel my baby away from me in her little fish-tank of a cot. I watch them wait for the lift to

arrive that will bear my baby and them away from me, up to the Special Care Baby Unit, two floors above mine.

A little later, the same porter and nurse arrive at my bedside and say they would like to move me off the main ward and into my own room “so you can get a bit more sleep” they say. I realise later that the hospital policy is to move mums with children who are ill or who have some kind of problem away from mums for whom things are going smoothly. I have mixed feelings about this; it is, I know, intended to protect vulnerable people from “normal” mums with “normal” children all congratulating each other and billing and cooing over their perfect offspring. In retrospect, though, it seems like the first glimpse of the loneliness of the life which is to come; a feeling that I don’t fit in to the world of normal parents and although everyone is so kind, there is also an embarrassment, perhaps a fear of saying the wrong thing, a secret worry perhaps that whatever is the trouble might be somehow contagious. A worry that having an abnormal baby around will spoil their own time of happy blessing. I have a feeling of living in a parallel world, of being outside looking in.

Later that evening, all the visitors have left. A sense of the enormity of all that has happened in that one short day begins to sink in. Most days go past almost unnoticed; the sun rises in the east and by the time it sets again in the west not much of significance has happened...but today...This morning I was just myself, as I have always been, but tonight, everything is different; I have brought another soul into the world. I stand at the window of my room and look across the darkness to the windows of another part of the hospital. It is cooler tonight, the season is changing, and I can almost feel the world rocking, rocking, and lulling us gently to sleep.

Chapter 3

I don’t know how long I stand there, looking out into the night, but when I hear the door of my room creak open and look round, the room has become dark. The light from the main ward shines brightly as a nurse I have never seen before comes into my room, flings her arms around me and bursts into tears. Surprised and bewildered by the outburst, I wait for her tears to subside, and for an explanation from her. We both sit down on the edge of the bed and the nurse blows her nose. She looks at me and says “It is such a blessing when a baby is born, but even more of a blessing when that baby is normal” She doesn’t expand on her enigmatic words and I don’t have a clue what she can possibly mean. I just look at her and wait, perhaps she is upset because a baby on the ward is ill or maybe there is a problem with her own child. I don’t get an explanation, however, and the nurse, now more composed, puts her hand on my shoulder and says, “now, is there anything you want? Can I get you anything?” “No, really, I’m fine thanks” I smile, still puzzled. It has been a strange day and everything is spinning round and round my head, so many enigmas, and things not quite making sense. Exhausted, I lay down on the top of my bed but no sleep comes.

The weekend goes past in a blur of visits from friends and relatives. There is no restriction of visiting times for babies on Special Care and the effect is like an “open house” party, although the nurses seem to be tiptoeing around me for some reason.

Monday comes. I feel in the way on Special Care as the nurses bustle about with their official looking clip boards and all their talk of pulse and temp and blood gasses. The baby is sleeping so I retreat back downstairs to the postnatal ward. I am listening to Woman's Hour on the Hospital radio headset lying on the top of my bed when I notice the doors at the end of the ward swing open and the obstetrician and his entourage sweep on to the ward. I can see onto the main body of the ward through my room's open door, and watch as they stand at the foot of the bed of each patient and exchange pleasantries and a laugh and a joke as they progress along the ward. As the consultant approaches my room I see the smile disappear from his face as the ward sister whispers confidentially in his ear. He nods knowingly and speaks in hushed tones to the junior doctor on his left. The tone of the group is subdued to say the least as they reach the foot of my bed. "How are you feeling?" the consultant asks tentatively. I tell him I am ok and he smiles kindly. There is no laughing and joking now. "Very good. Well then we will leave you in peace to enjoy your radio programme" He backs away. The incident puzzles me. I must look tired, perhaps he has noticed. I would like to know what the nurse whispered to him though.

I sit talking to my auntie with the baby, still with no name, sleeping in her cot beside us. "I suppose nine months didn't give you enough time to choose a name!" She laughs. "I still can't decide," I explain. I never imagined it might turn out to be a girl, I was so sure we were going to have an Edward" I see Dr Dodds talking to the other medical staff in the office, obviously in some kind of case conference about someone. I see him nod his head and leave the office. To my surprise he walks towards me and pulls up a chair to join auntie Sue and myself. He begins by asking general questions about how the feeding is going, and I think he is just being friendly. He gets up and looks into the baby's cot. "Do you mind if I pick her up?" he asks. His question surprises me, as I don't feel as if the baby is really mine, but that she is some sort of hospital property, belonging to the nurses. "Of course not" I say with a laugh, thinking he just wants to admire her. He holds her close to his face and looks intently at her. He turns to me "what do the family think of her?" Strange question. I don't really know what he means, and still think what is happening is a sort of social call, don't feel the earth tipping beneath my feet; don't perceive how close I am to the edge of the cliff. I glance at Auntie Sue and smile. She smiles back weakly but looks uneasy. I don't know what to reply, what would be the answer he might be looking for, what would be the correct answer? "They think she is quite something," I offer. Dr Dodds looks uneasy too. "Has she had any wet and dirty nappies" I nod. "That's good, we know things can go from one end to the other so we don't need to investigate that then." Carefully, he hands the baby to me and pulls his chair a little closer to mine. Here it comes. By the end of the next sentence my world will have changed forever. "I think there is one more test we need to do, though" he hesitates, searching my face. I still don't know what he is talking about. I smile encouragingly "I think we should do a chromosome test" He pauses and looks intently at me. The penny still doesn't drop. I continue to smile at him, waiting for him to get to the point. He is silent, waiting for some signal from me that I am following him. No signal comes so he delivers the blow anyway "For Downs". He continues to look at me and the seconds seem like hours. My brain hears the words the doctor has just said but attributes no meaning to them. How cleanly the knife goes in. I feel nothing at all. I know a knife has gone in but I feel nothing at all. Everything feels far away and I feel disembodied. I look down at the baby in my arms. I study her face.

Down's? What is he talking about? This is my baby. How can she have Down's? Ordinary people like us don't have children with Down's. I can sense that Dr Dodds is still speaking but I can't make out what he is saying. I don't even try to listen; What he is saying can't possibly have anything to do with me. He must be talking to someone else.

I am floating, looking down from the ceiling at three people sitting with their chairs huddled closely together. One of the women is wearing a blue dressing gown and holding a tiny baby, and is looking intently into her baby's face. The group sit motionless but the man in the group, dressed in a blue short-sleeved shirt is looking at the woman with the baby and is speaking to her in a quiet, soothing voice. The other woman in the group wearing a black and white dress is looking away and dabbing at her eyes under her glasses. I feel a strange disinterest in the scene I am watching, which is as still, as poignant and as silent as a tableau.

Slowly, I see myself descend back into my body, and I look to my right to see that Auntie Sue has tears streaming down her face. She is obviously taking the news on board much more quickly than me, and at the time I wonder at her tears. Dr Dodds is still talking..... "She does have one or two features which make us think of Down's syndrome." I continue to look at my baby's face. He is obviously making a big mistake. She looks perfectly all right to me. "She does have a single palmer crease, for example" "A what?" I ask? "What's that?" "It is a single crease on the palm of the hand which can be an indicator that something has gone wrong very early in the pregnancy" I say nothing but gently turn my baby's hand over and spread her tiny fingers. I feel like a traitor, uncovering some shameful secret of my 2 day old infant; my changeling. As I stare at her palm I hear the low note of a deafening tolling bell deep in my soul. It is so loud in my ears that it makes me catch my breath. Instead of the creases that would normally criss-cross the palm of a human being's hand, one straight line traverses the centre of the palm, like a healed gash. It is undeniable, plain for anyone to see. "We would like to take a small amount of blood and then we will send it away for analysis" This seems like a terribly traumatic intrusion. I had expected the early days and weeks of my baby's life to be a beautiful time of grace and peace, now a stranger is going to start sticking needles into her perfect newly minted flesh. "Where will they take the blood from?" I ask, looking at the smooth skin of her arm as I anticipate his answer. "The scalp." I feel sick as I look at the almost transparent skin barely covering the bony skull. "But what will you do if she has Down's" I ask, stupidly. Although I know perfectly well that Down's syndrome is an undeniable, permanent condition, affecting every single cell in a person's body, I suppose any other illness or condition I have been personally exposed to either disappears in time or can be treated by medication. Part of my brain assumes this will continue to be the case, whatever the condition. "Well, we will tell you," says Dr Dodds, simply. I feel the knife twist now, as a tiny bit of the reality seeps in. Dr Dodds rises from his chair. "We would like to take the blood first thing in the morning and then we will send it off to the lab in Leeds, ok?" I nod and smile weakly. As Dr Dodds leaves, one of the nurses comes out of the office and asks me if I would like a cup of tea. She knows already! An accomplice! I feel betrayed. I feel stupid. It all begins to make sense. My head is in a whirl. I think of the tearful midwife, the sheepish junior doctors, the pitying looks of the nurses, my move off the main ward into the single side-room. I am the last to know, it feels like a conspiracy.

I continue to stare down at the baby in my arms. I am aware of my weeping aunt's arm around my shoulder, intoning soothing words in my ear, but I hear none of them. I am sinking down, down, down under the water, retreating far away from this nightmare. I cannot speak. You can't speak when you're under the water. What would be the point anyway? Nobody would be able to hear.

Chapter 4

I think of Offenbach's lyric "When you can't have what you love, you must love what you have" But I can't. I'm not cut out for it. I'm not up to the task. How can I possibly look after a disabled child? I can't love what I have.

On the Special Care Baby Unit, there is a very special room funded and supplied by Marks and Spencer. It is known simply as "The M&S Room" It is like a little self-contained flat, with a sofa bed, television, tea and coffee making facilities, en-suite shower; all mod cons. I stay in this room all day, staring at a sampler hanging on the wall above the kettle. "Lord keep us safe this night, secure from all our fears, may angels guard us while we sleep, 'til morning light appears" I stare at the neat stitches of the sampler and say the words over and over to myself, like some sort of mantra, but the more I say them, the less power or truth or meaning they seem to have, I can feel God retreating, like the power retreating from Jerusalem's temple. I wonder whether He has the power to stay and influence the happenings in my own little world, whether He ever had or have I been brainwashed and misled all these years by the Church into thinking He was there at all... Maybe even if He was there, would I want Him to stay, if at a stroke He could do something like this to me and to my innocent child?

It is not only the natural world that is tipping on its seasonal axis, but I can feel my own world tipping, like my own private earthquake.

Later that day, as I stare out of the window into the hospital car park below I realise with panic that this is the time when the influx of visitors arrive, all of them, including Peter, unaware of what has happened. I feel I am deep below the water; unable to think coherently, much less speak. There is no question of me being able to put into words what has happened. I cannot deal with the questions, tears, condolences, and platitudes. There is no question of being secretive or even depressed about the situation as I am later accused, as an explanation for my withdrawal from other people, simply that I cannot physically raise myself far enough above the drowning, choking water in order to speak. I tell the nurses to tell nobody where I am and under no circumstances are they to be persuaded to let anyone into my room. There is also the feeling that putting the situation into words will make it real, and that by hiding in this cocoon of the M&S room, the whole thing is indeed a nightmare, but can remain just that, a nightmarish dream. If reality is not allowed in, the situation will not become a reality. There is a tiny knock and Nurse Bridget peeps round the door. She has heard about what has happened and has come to offer support. I stare at her, but no words come. "You must enlist the help of your family," she says. "How are you and your husband taking the news?" When I tell her Peter doesn't know yet she can't

believe it. “It is a family crisis, and you have to deal with it as a family” I know she is right, and I know that any one else would be surrounded and supported by their family, but I just feel I do not have the words to explain, or the strength to deal with anyone else’s reaction. If I tell one person, I have to tell everyone. Some people would deal with the situation so much better than others and would not add to the burden, but others would add to my distress by reacting extremely badly, with anger perhaps, or with a deluge of questions to which I would have no answers. The safest thing is to hide for the time it will take for the test results to come back; a week, a long and lonely week. At the end of the week, if the results are positive, I will tell everyone then. If they are negative, they will not have had to endure the waiting and worrying.

Looking back,, I realise how flawed this reasoning was, on so many levels. It was all about words; not having the words to explain what was happening, not having the energy to deal with other people’s reactions, not having a model of how I should behave. Thankfully, Bridget persuades me to tell Peter, which I do. He acts with total incredulity and anger. “Just because she isn’t putting on weight it doesn’t mean that she has Down’s syndrome” I point out the single palmer crease and try to remember and explain its significance, but he is still wholly unconvinced. “Anyway”, he breezes, “I am organising a seminar at work this week so I haven’t even got the time to think about it ‘til Thursday. It will all be a storm in a teacup” He sings “Goodnight Sweetheart” to the baby, kisses me on the cheek and goes into the kitchen to make a drink. I sink down another few metres into the silence of the murky water.

Chapter 5

In the days that follow I sleep, wake up, cry, sleep, wake up, cry, sleep. The baby not only refuses to put on any weight, but also does not even slow down her accelerating weight loss. Although I am breastfeeding, nobody explains to me the importance of feeding frequently, or anticipates the problems that sleeping on separate floors of the hospital will inevitably bring. I awake in the night a few days after the birth in excruciating agony, as my milk supply comes in. The natural thing would be to feed the baby, who will now be ready for the increased volume of milk. I don’t know this and nobody tells me this. I just clutch a towel around my leaking, heavy breasts and wonder what on earth is happening to me.

“What shall we call her?” asks Peter; “everyone is asking what her name is,” I hadn’t even thought. We seem so stuck in this surreal situation, in no man’s land. I cannot envisage ever getting out of the hospital with her, never having any real life again. Why does she need a name, she is not even a proper baby, just a condition. “What about Daisy?” says Peter, “after Grandma” “Fine” I mumble, not really interested. “Daisy it is”

I wish I could pray. I wish I had my old faith back. How many times have I heard about faith becoming strong and real only when it is tested? Well here it is! Here is my time of testing, and I look around for my faith and it has vanished like a vapour. Most Christians, I am sure, true Christians, would at this very moment be surrounded

by family members, church members, shoring each other up, sharing the burden, coping, praying, crying, laughing through the tears sometimes. I feel only the icy coldness of a barren place. I feel truly alone. I feel a failure. I have no words to share with man or with God, whoever He is. I think of all the people I have heard sharing their experiences on religious programmes on TV; people talking about traumatic experiences in their lives, or in the lives of loved ones, and how they felt the loving arms of God around them, comforting them, strengthening them, even, perhaps in the face of death itself. Here I am not confronted not by the reality of a death, but with a questioning of God's power and influence, and I feel so dismantled. I am looking at the world differently; wishing it could go back to how I thought it was before. I think of Thomas Hardy's poem "The Oxen" describing someone experiencing a similar feeling of vanished faith, and wishing that unquestioned, unchallenged faith could be mine once again.

Christmas Eve, and twelve of the clock
 "Now they are all on their knees"
 An elder said as we sat in a flock
 By the embers in hearthside ease

We pictured the meek mild creatures where
 They dwelt in their strawy pen,
 Nor did it occur to one of us there
 To doubt they were kneeling then.

So fair a fancy few would weave
 In these years! Yet I feel,
 If someone said on Christmas Eve,
 "Come; see the oxen kneel

In the lonely barton by yonder coomb
 Our childhood used to know"
 I should go with him in the gloom,
 Hoping it might be so.

I feel so much that I would love to go with anyone with his or her own faith tested but still intact, hoping it might be so.

Chapter 6

I go down to the antenatal ward for a bath and I hear the hubbub of normal mothers and babies and nurses. They may as well be on another planet from me. I feel so different. I have nothing to rejoice about. I wish I could change places with one of them.

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During the days that follow, a terrible situation unfolds on the Unit, to which I feel inextricably linked and responsible. A baby is born on Delivery Suite who is gravely ill, and is admitted to the Special Care Baby Unit. Her name is Angela; my own sister's name. Later that day two nurses come into the M&S Room and ask me if Angela's mother can have my side room on the ward; I hardly go there now anyway

as the M&S room has a camp bed on which I sleep (or lie awake, to be accurate) so naturally I agree. Angela's mother is ill too, it seems, following a traumatic birth, and so the midwives need to keep a close eye on her. I go down to my room on the antenatal ward and clear out my belongings so that Angela's mother, called Rachel, like me, can be moved in.

The atmosphere on Special Care is palpably grave. The room in which baby Angela sleeps is kept dimly lit. She sometimes sleeps in her cot, she sometimes sleeps in the arms of one of the nurses. There are frequent visits from her serious-looking consultant. Each time I see a nurse I ask the same question; "How is Angela?" and each time I receive the same reply; "Not good"

Each night after each long and lonely day I go down to the antenatal ward for a bath. I walk past my old side-room. On the blackboard showing who is in which bed I can see the ghost of my name in the chalk, and the new Rachel's name written over the top; the name of the person who has taken my place.

Feeding Daisy is an absolute nightmare. She takes an age to latch on, getting more and more frantic and wearing herself out crying so that she is too tired to take any milk. Her weight loss continues and the medical staff appear more and more serious. I think they blame me. I can't do it. Daisy's life depends on something I can't do.

The concept of bargaining, exchange, changing places and pacts begins to preoccupy my thoughts. God, or the forces of nature, requires taking a baby. It seemed that for a time that baby was to be mine. I wished I could change places with someone. Could wishing make it so? Has God for some reason decided to single out my baby, and then sees that I am not up to the challenge, so has to single out another? Day and night blend into one...this is the twilight zone...anything could happen...new souls are coming into the world.... and maybe departing from it.....

I find myself playing human simultaneous equations in my head 1 normal baby = 1 normal baby. Maybe 1 ill one = 1 Downs one. Dare I say 1 reprieved one = 1 dead one? Dare I suggest that? Ask for that? Maybe it is possible to trade 1 dead one for my normal one? Would that balance the equation? Wordlessly, silently, guiltily, I make the offer.

I shiver inwardly as I pass my old room. The door is ajar. I can see the windowsills where a few days ago my celebratory vases of flowers and cards stood. It is bare now except for a pale blue wash bag. The room is silent. The sense of grim anticipation is palpable.

When I arrive on Special Care Angela's room has the blinds drawn and is in complete darkness, save for the flashing monitors around her cot. I avoid the eye of the Consultant leaving her room and creep into the M&S room.

The next morning, as I go to check on Daisy in her little fish tank-like cot in the baby's room, an audible, deafening note of sheer terror strikes into my heart. I can feel it in my stomach like the lowest note played on a double bass, for outside Angela's room is a pale blue old-fashioned Silver Cross pram. From my days working at the hospital I know that this is the mortuary's vehicle for transporting the

bodies of babies who have died between ward and mortuary. The Consultant is leaving Angela's room again. His eyes are red-rimmed from crying or as a result of a sleepless night or possibly both. He nods to me and smiles. I manage a weak smile. I go back to the M&S room, sit on the edge of my bed and stare at the floor. I feel like a murderer.

I feed Daisy for most of the morning, clinging to her living flesh, as I hug myself and rock to and fro, stroking the pulsating, fontanelle, reassuring myself that she is mine to keep. I feel sick with guilt when I imagine the price that has been paid to enable me to have this moment.

That evening, after I have fed Daisy I go downstairs on to the Ward for my bath. As I come out of the bathroom later I see the most terrible sight. The sight I witness in those endless moments has remained with me for all the months and years, which are to follow. Even in my happiest, sunniest moments, the image of it is never far away, and it returns often to cast a zero chill over my life. There are two nurses outside my old room. The new Rachel in the old Rachel's room. One of the nurses holds open the door of the room, whilst the other pushes in the pale blue Silver Cross pram.

I return to the bathroom I have just left, lock the door and am violently sick. By rights it should be me in that room, holding the tiny form of my own dead infant, and whispering goodbye. In many of my nightmares in the following years, it is me who waits in the room whilst the nurses push in that pale blue Silver Cross pram.

Chapter 7

The following day is Friday. I open the huge pivot window in the M&S room and look down into the hospital car park, where the people who keep this huge ship afloat are arriving for work. Although it promises to be a sunny day, there is something in the air that speaks of autumn, a mistiness of the light, a slight nip in the air, an earthy smell of decay. The season is changing. The earth is rocking.

The emotional trauma of the last week has been exhausting, and after feeding Daisy I curl up on the sofa and drift off to sleep. I am roused from my slumber by voices outside my room. The door opens and one of the nurses comes in. I see the tall figure of Dr Dodds behind her in the doorway. I am instantly awake and I feel my heart pounding, about to leap out of my chest. The nurse winks at me and I take this to be a good sign. "Does he have the result?" I ask her but she doesn't answer. I look at Dr Dodds pleadingly. "Do you know?" He sits on the sofa beside me and smiles. "I have some good news for you" he says simply. "I collapse back on the cushions. "Oh thank God," I say, and I really mean it. I don't hear anything else he says but am aware that he is still speaking. My brain can't take it in all at once, but she doesn't have Down's. Nothing else matters. I have a normal baby, life can begin again. What else in the world could possibly matter?

"...Chromosomes...weight loss... negative for Downs..." Before he leaves he reaches into Daisy's cot and strokes her cheek fondly. I am too dazed, too exhausted, to take in the news fully but after he has gone the floodgates open and I cry and cry and cry.

I ring Peter at work and tell him the news. He sounds pleased but surprisingly calm. He hasn't been so deeply affected as me. I do not feel he has been through the valley of the shadow with me. We have been so out of touch with each other and I realise I don't really know how he has been feeling, and haven't communicated how I have felt to him. I suppose all my thoughts and fears about the fairies; the changelings, swapping places and pacts with God were too fanciful to share, impossible to put into coherent words. He would have thought I had taken leave of my senses. No matter, it is all over now, plain sailing from now on.

I tell Peter that we can explain to everyone what the problem was and that now we can see people again. I begin to feel euphoric, like every mother of a normal child feels, I suppose. The sorrow is truly behind us and the wonderful future lies ahead. Of course there will be tears mingled with the laughter like in every normal family but we will be just that; a normal family. That night the M&S room is filled with laughter and congratulations and tears of joy.

I decide not to go down to the ward for a bath that night; I will have a shower on the Unit in the morning, besides, I'm too tired.

Chapter 8

I imagine that after we have the official "all clear" everything will miraculously be hunky-dory. Not so. Daisy continues to be very difficult to feed and her weight continues to drop. At birth, her weight was 6lb 4oz. It is now below 5lb. The nurses weigh Daisy every morning and every afternoon and I begin to dread these sessions at the scales. I feel they may as well just shout, "what are you doing? You are obviously not up to the task of feeding her properly!" I don't know what to say to the nurses who I feel to be cold and accusing. I want to tell them I am doing my best, I don't know what else I can do, but I just feel my confidence sapping away from me as I look at the numbers on the weighing scale; slightly lower than they were this time yesterday.

I feel I will do better if I were in my own home, although we have sold our house and packing boxes are everywhere. We have agreed with our buyers to move out in a matter of weeks and we have been unable to find another house to buy. We have no idea where we will be going.

As the days turn into weeks, I tentatively ask the most approachable of the staff nurses when she thinks we will be discharged. She shakes her head gloomily. "We don't usually let babies go until they have regained their birth weight," she tells me. This news horrifies me. I cannot imagine Daisy ever regaining her birth weight. Part of me believes we are stuck in a kind of time warp, and that Daisy will never thrive and put on weight. I don't anticipate that she will die, just that we will somehow remain like this, forever. Although the staff seem obsessed by constantly weighing Daisy no one talks (to me, at any rate) of any possible reason for the weight-loss, or of a plan to turn things around. If only I could get away from here, where normal life would be around me, then surely things would become normal for us too. I even contemplate a plan in which I effectively kidnap my own child and do a runner through and out of the hospital. I have worked here for some years and I know all the shortcuts and

passageways to the little-used back doors. I would never get away with it though; they would surely catch me and bring us back. Even if I did make it to the door, I would require an accomplice, otherwise how would I get home? I would never get anyone to agree to help me; all my family and friends are so sensible, but they have absolutely no idea what it is like to be in here, or about the pacts that have been made here in secret.

In the end I use a powerful weapon with Dr Dodds; tears! I beg and plead. "Please can I go home?" I can see in his eyes that, although reluctant, he is relenting. "You would have to bring her back to the Unit every day" "Of course" I promise. "I will bring her every day for the rest of her life if need be" The words chill me as soon as I have uttered them. How long or short might that life be?

.....

I sit with Daisy in the back of our blue Ford Fiesta as Peter drives us home. It feels so weird to be out of the confines of the hospital and to be part of the real world again. I look at everything as if with new eyes; the houses, the trees, the cars. It seems as if the last time I felt the breeze on my face was in a previous life. In many ways it was a previous life. During the time we have been in hospital, my whole life has been turned upside down. I feel an overwhelming sense of relief as I walk through the front door. Now we are home everything is going to be fine.

Chapter 9

I feel overwhelmed by how much my life is turned upside down by this squawking, demanding creature in the house. I truly feel that she is the enemy, that it is me against her. I wonder that nobody told me how truly awful life with a newborn baby would be. I am lost for words when, one day out walking with the pram, hardly able to put one foot in front of the other, far, far beyond exhaustion, a lady stops me and asks if she can look into the pram. She beams at the sleeping Daisy. "Make sure you treasure these days" she exhorts me. "They are the happiest days of your life!"

It is not just that I am busy with the practical work that any baby generates, but I feel my foot is well and truly nailed to the floor; Daisy can take up to four hours to take a feed. I sit at the dining room table; the only place I can get comfortable, and look around me at the chaos; piles of unwashed clothes, dirty cups and plates, even more depressingly, books and papers for my degree which now seems destined to remain unfinished, tantalisingly with only a couple of terms to go. I also feel shocked and exhausted by the emotion generated by the last few weeks, although it has apparently come to nothing, as Peter predicted, the shock waves that I feel within me have changed the way I look at things; things that seemed certain now feel undermined and questioned. And yet because of my inability to communicate what has happened, it seems that I am alone still. It feels a little bit like gunpowder plot; the nation is changed and influenced and absorbed for all time about something that never actually happened.

Every day I bundle Daisy into her car seat and pack blankets around her, as the seat is ridiculously large for her. I drive her down to the hospital paediatric clinic. As I

undress her and place her on the scales I am falsely cheerful, laughing and joking with the nurses. I know that if I let this façade drop for a second, I will begin to cry and cry and may never stop. If that were to happen, they would know I were unable to cope and might take the baby from me. The nurse writes down the weight on Daisy's notes and I see that it is an ounce or two less than yesterday. Daisy's skin looks pink and dry as she cries on the scales. Her skin feels to slip over her bones as I struggle inexpertly to dress her. I feel ashamed as I sit facing Dr Dodds later in his consulting room. He is not a man of many words but I can see on his face that he is concerned. Each day he plots Daisy's length, weight and head circumference on the centile chart before turning the notes around so that he can show the chart to me. I do not know what to say. I feel every day that a teacher is showing me a piece of badly done homework from the previous night. No words are necessary so none are spoken. The chart speaks for itself. I have failed today as I failed yesterday.

It is Friday and I sit facing Dr Dodds once more, the chart lying accusingly on the desk between us. Although Daisy is no longer losing weight, weight gain is so painfully slow that the trend on the growth chart is still following a downward trend. At two and a half months old Daisy has still not regained her birth weight. Dr Dodd's face is grave as he rubs his chin. "I think we have to do something," He says enigmatically. "I think we have to put her on formula milk. The content is fatter than breast milk and she needs the extra calories" Sadly I agree. It is official. I am failing. I cannot do the most natural thing in the world. I cannot even feed my own baby. I have always been anti bottle feeding, feeling it is the domain of the mother who can't be bothered to give her baby the best and most natural, fitting start in life, who denies her own baby not only the best nutrition, but also denies what breastfeeding symbolises to me, a pure and graceful welcome to life, the warmth and peace of human generosity and comfort. It seems a poor, mean substitute to offer the impersonal cold plastic bottle of factory made chemical "formula" the very name of which sounds man-made and synthetic to me; something any Tom, Dick or Harry could administer, not uniquely to be given by a loving mother. It is something I desperately do not want to do, and never thought I would do, but do it I must.

Although we have agreed a sale on our house, and have now found a new home, there will be a gap between moving out of the old and moving into the new of about 6 weeks or so, and we are kindly given the key to the door of some people from our church who are visiting relatives in Germany. I feel like the holy family at the first Christmas, as we put down Daisy down in her car seat amongst plastic bags and cardboard boxes in the unfamiliar hallway. I am still determined to breastfeed Daisy at least partly, and whilst Peter is at work I sit on the floor of the little bungalow and feed Daisy. To my delight I find "The Best of Morecambe and Wise" video which keeps me laughing whilst feeding Daisy hour after hour. Fortunately when even the sketch with the ball and the brown paper bag is beginning to wear a little thin, I find "The best of Tommy Cooper" at the back of the video cabinet. See? Life is rarely completely grim!

When our friends return from Germany we are on the move again; this time to the large gothic-looking home of some more friends from church who have gone away on holiday for two weeks. I feel homesick and miserable. Despite giving Daisy formula as well as breast milk, I can see her getting thinner and thinner before my very eyes. My life seems increasingly bleak. The house in which we are staying is about half an

hour's walk away from the hospital and I spend all my days either getting ready to go to the hospital, or waiting at the hospital or getting back from the hospital, or crying because my experience at the hospital has been far from encouraging, and Daisy has lost weight yet again.

"Is it the hospital again today?" Peter asks as he ties his tie. What is Daisy going wear?" "No idea," I admit, "why do you ask?" "I was just thinking, if she looks smart and well cared for they would think we are coping. They might not be as quick to take her away from us if they think we can manage" Peter calls over his shoulder as he leaves for work.

Propped on the piano in the sitting room is the music for an old-fashioned lullaby "Golden Slumbers Kiss Your Eyes" Tears stream down my face as I play the lullaby inexpertly to Daisy. My mothering seems so far away from what it is supposed to be, what I imagined it would be.

On Sunday we load spare clothes for Daisy into a bag and set off for church. It is the first time we have taken Daisy to church and I had imagined this time with happy anticipation since long before the birth. Everyone would be delighted to meet my rosy, bouncing baby and to pass her adoringly from person to person. The reality is so much different. Two weeks before Daisy was born a baby was born to another couple at the church. It is the first time I have seen this baby boy since before the birth of Daisy. I gaze at him open-mouthed when I see him dandled upon the knee of his grandma. He must be literally twice the size of Daisy. He fills his clean blue baby grow with his healthy-looking chubby limbs. His big blue eyes sparkle as he looks into the face of his smiling grandma with contented recognition.

There must be something wrong with him; surely it is not normal for such a new baby to be so enormous. I feel confused and jealous as I look at him and his family looking so happy and in control. I feel such an outsider, as if I am stretching my fingers out towards everyone but that normal life is retreating further and further from me. I stay in the library at the back of the church during the service so that I can feed Daisy in private. At the end of the service I slip out of the building before anyone has the chance to see us.

Chapter 10

At last the day arrives when we can move into our very own house. The house is in a nice village close to where my mother and my sister and her family live and I look forward to receiving the support I need and which they can offer. I feel that at last now we are in our own home, things will settle down and Daisy will begin to make progress. Feeding Daisy continues to be the main, the only focus of my life. She falls asleep at the breast after a few minutes. If I try to bottle-feed her I think it is a minor miracle if she takes half an ounce of milk She usually brings back the little she has taken anyway.

Despite all my best efforts though, combining breast and bottle-feeding, Daisy's static weight, or incredibly slow weight-gain, or sometimes-even weight-loss at the hospital weighing sessions continues to worry Dr Dodds. Until now, I have been feeding on demand, but Dr Dodds now advises two hourly feeding day...and night! The nights until now haven't been too bad and we have been managing with being woken maybe once in the night, or even perhaps with only a late night feed before we turn in, and getting up to feed at may be six or half-past in the morning. All that is about to change. Dr Dodds leans back in his chair and studies the accusing centile chart. He asks me about Daisy's typical feeding pattern. He listens quietly to me hesitating and stammering trying to pretend I have the whole feeding thing under control. Until now I have been proud and relieved that she sleeps well in the night, comforting myself that at least she must be taking enough nourishment during the day to satisfy her, otherwise she would be crying all night. That delusion is about to be shattered; "I think she doesn't wake in the night for a feed because she is becoming too weak to cry, which is dangerous. We should feed her every two hours night and day whether she cries or not" Dr Dodds sits beside the emaciated-looking Daisy on the "cabin-bed" – whilst I fumble with the fastenings of her sleep-suit. As I struggle to dress Daisy it occurs to me that suspicions must be being raised that my child may be at risk. Perhaps Dr Dodds is at this very moment gathering evidence that could be used to take Daisy away from me. My heart sinks a little deeper. A horrific picture flashes into my mind of a stern-looking foster mother wrestling a screaming Daisy from my arms.

As I collapse exhausted into bed I reach over to the little brass clock at my side and set the alarm for 1.30am; two hours hence. My mind is in a black whirl; even my best efforts seem worthless and futile. I feel I am spiralling down and down into darkness when the set of three notes from the alarm clock trill into my consciousness. I drag myself out of bed and stumble into Daisy's dark room. I sit shivering in the dark room an hour later feeding Daisy after I have eventually got her to latch on. She falls asleep after swallowing only a few gulps of milk. I know I should go down into the freezing cold kitchen to warm a bottle of formula but the lure of the warm duvet and oblivion is overwhelming. Sitting on the edge of the bed I set the alarm for 3 am; Peter's turn thank goodness. Poor Peter, he is always up longer than me because whilst Daisy sometimes brings back breast milk, she always brings back formula, so the whole process has to be repeated at least twice. I lie awake trying to elicit what stage they are at by the sounds I can hear from downstairs. This torture continues relentlessly night after lonely night. I sometimes look out of the window over the sleeping village. All the curtains are drawn and all the lights are out. I imagine all my neighbours sleeping peacefully and undisturbed in their cosy beds. I envy George, who lives alone in the bungalow across the road. Many would pity his lonely life but I would change places with him so readily. Every evening I hear the click of his garage door and his car engine running on the drive as he prepares to depart for his nightly visit to his local. He will return with equal predictability an hour and a half later. His life seems so ordered and "normal" whilst mine, only a few metres across the road, is falling apart, and seemingly slipping away from my control.

I sometimes wonder who will be the first to finally lose control and actually kill Daisy. I sometimes plan in my mind how I will do it when it all becomes too much for me. I imagine driving Daisy and myself to some lonely spot near a local reservoir,

and poisoning us both with exhaust fumes. The only thing that stops me is the thought of the inextinguishable grief for our families of which I could not bear to be the cause. Every night I worry that Peter's solution would be as a result of him losing his patience; his will to carry on. I imagine him holding a pillow over the tiny face until the breathing stops. When his watch is over and he comes back to bed in the silent night I dare not ask "Is she alive?" Instead I lie awake in the darkness, dreading hearing another cry, dreading not to.

Chapter 11

It is a dark and drizzly Friday towards the end of December; the day of my brother-in-law Andrew's surprise 40th birthday party to be held at our house. Daisy is dozing in her cradle chair beside me whilst I bustle about in the kitchen making a huge panful of chilli-con-carne for the party. Familiar voices from Radio 4 chatter soothingly. Normally never happier than when I am pottering in the kitchen, especially with the prospect of friends and family coming later to share the food, but today I feel increasingly uneasy about Daisy. There is an unusual stillness about her. She looks so thin today and her skin has an unusual bluish tinge I have not noticed before. When I touch her skin she feels burning hot. Perhaps she is simply feeling too hot in the warm kitchen, after all, the radiator is on, the oven is on and the windows are all tight shut against the December cold. I strip off Daisy's clothes and leave her lying on a blanket wearing just a nappy. A few minutes later I hear a knock at the door and am dismayed to see my health visitor. She has the unfortunate air of someone who appears disapproving by her silence but who never offers anything useful in the way of advice or encouragement. She also has the irritating habit of referring to "Baby" rather than "Daisy", I assume this to be because she is not interested enough to commit my baby's name to memory. "Don't you think it seems a bit cold for Baby to be undressed like that" She gestures across the room with her cup of coffee. "Well" I feel accused by the words. "She felt so hot so I thought she would be better with a bit of air" "It is a bit warm in here" she concedes, but maybe just a little vest or a thin blanket..." As Nurse Wells tells me of the plans for her daughters wedding, brushing the crumbs of chocolate cake from her suit with her manicured fingers, I can see in her eyes that she too is uneasy about Daisy. "Is she feeding well?" she asks. "Oh not too bad at all really" I lie; "I feel increasingly suspicious that Dr Dodds is looking for a reason to take her from her incompetent mother, the last thing I want is to alert my nosey Health Visitor to the fact that I am not coping with my own baby.

As the afternoon wears on Daisy's condition appears to worsen. Her cry is heart-rending; different from any cry I have heard before, and has a kind of whining quality about it. She hasn't fed for pretty much all day. I feel sick in the stomach as I lift the 'phone to the hospital. I tell Dr Dodds the situation and he listens quietly and kindly. He is always kind. "How soon can you get here?" He asks simply.

Half an hour or so later in the waiting room of the paediatric outpatient clinic Daisy is fast asleep in my arms. She opens her eyes momentarily and promptly throws up spectacularly all over me. I have got spare clothes for Daisy of course, but none for myself and I awkwardly try to fish in the pocket of my coat for a tissue to mop up. I

feel clumsy and inadequate and on trial under the watchful gaze of the nurses at the desk. Dr Dodds is obviously worried about Daisy's condition and arranges for her admission onto the Ward and we are installed into a side-room. Daisy's cot is large and institutional-looking with its metal sides and starched hospital linen.

The days come and go and each day Daisy seems more ill, more unresponsive, thinner. She can tolerate no milk by mouth and so is fed via a nasogastric tube. A canula is placed in her tiny hand. Her skin looks like paper where the drip enters her tiny body. She is slipping away from me. I gaze down at her, resting my chin on my hands over the cold metal bars of her cot. I feel that she has never really been mine; she belonged to the nurses in those early weeks on Special Care, then I only had her on loan but still under the watchful and critical eye of the medical staff at the hospital, and now she has been reclaimed. I feel a hand rest around my shoulder, and a presence beside me. I look around and see my father-in-law, obviously on his way home from work. He is not a demonstrative man, and his quiet presence means such a lot to me. Neither of us speaks as we look down at the sleeping Daisy, her presence here on earth seems so uncertain, as she hovers there, between life and death.

I had wished and pleaded and bargained to keep her, for her life to be spared. Perhaps such a deal does not come without a price. Perhaps a reprieve, if granted, is only temporary. "Be careful what you wish for"

We are flattened by the news that a very special friend, Margaret, has died. A true lady, with a quick, intelligent mind and an outrageously naughty and playful sense of humour trapped for many years in a body suffering the cruel effects of Parkinson's disease. Although members of the church, her only "family" have been encouraging her to accept the safety of a care home, she has resisted this with her customary feisty independence. The cruel end comes when she stumbles and falls into the fire in her living room. As an old friend of Margaret's, my grandfather-in-law, "Granddad" to many people is asked to say a prayer at Margaret's graveside. Peter attends the funeral whilst I stay at the hospital with Daisy. The December day is achingly, biting cold. Granddad stands by the grave and trembles with the cold, the emotion and with something else too. "Hold on to my hand" he whispers to his devoted wife, Daisy, "and I will be alright" But something happens to him that cold December day, and it seems as though death is mighty all around, and has caught sight of him too.

A week or so before Christmas, Granddad is admitted to the same hospital as Daisy, suffering from heart failure. Initially, we don't realise the gravity of his condition, and think he has simply overdone things, exacerbated perhaps by a chill caught at Margaret's graveside, and we expect he will be back home within a day or two. Going to visit him on the ward feels like a relief from sitting hour after hour beside Daisy's cot. Always a pleasure to spend time with, we laugh together about this and that, munching our way greedily through the chocolates and grapes people have brought for him. "Thanks love" he beams gratefully at the nurses who bring him drinks, or who check his pulse. He looks fine. He will be back home for Christmas.

It is late in the evening. All the visitors have left long ago and I sit beside Daisy's cot stitching a sampler. My mind has no rest and I can't settle to read anything, so it is soothing for my fingers to be busy. I need to have something permanent to remember Daisy by. I need to record her presence in the world and my fingers busily record her

name, her weight, and all the things that cannot be denied me or taken away from me in the long and desperate lonely years that will surely follow. I hear the heavy doors of the ward swing open and recognise Dr Dodds' footfall on the corridor outside Daisy's room. "How is Daisy?" I hear him ask the nurse at the nurses' station but I cannot make out the hushed reply. Dr Dodds pops his head around the door and attempts to smile. "One day at a time eh? Are you managing to get any sleep?" he enquires. "Why don't you go home and come back in the morning, you look all in" His words are so kind and thoughtful, I have to fight back the tears. I truly am exhausted; weary through lack of sleep, weary through worry, weary through trying to "keep thinking positive" as my mother-in-law constantly exhorts me to do. "Why don't you come back first thing in the morning?" he asks again. "We will ring you if we think you need to come back" There. He has said it. He thinks there is a possibility she might die too, otherwise why would he have said those words. I daren't ask if that's what he means. He is a good, honest man and I know if I tried to frame a straightforward question, he would give me a straightforward answer, but I just daren't ask the question. I feel that asking the question, putting it into words, might make it happen, so I work on the principle that if I can't see it, it can't see me.

The next day I am standing by the window, head propped on my hands, looking out at the midwinter scene. It is freezing cold outside and the trees and grass are rigid with hoar frost. The door creaks open and I look around. In the doorway stands the hospital chaplain wearing a grey sweater over his clerical collar. His words are direct, and pierce my soul with their macabre, undeniable implication "I am sorry to hear that your baby is so poorly; would you like me to arrange for her to be christened here in the hospital?" He looks at me and waits for an answer. I am stunned that he asks me like this; surely we should be sitting down, he should have gained my trust, asked about my faith, held my hand, but the words are called from across the room in such a way that I feel that I have been punched in the stomach, not been helped and supported by the Church. "No thank you" I tell him "We are Christadelphians, we don't christen children in our church" He nods in response and closes the door behind him. I turn back to the view from the window. The season has changed again. Tippet's words come into my head; "The world turns on its dark side. It is winter."

I think about planning the funeral for Daisy, but the more I contemplate it, the practical impossibility of planning such an event seems insurmountable. The only funerals I have been to have been those of old people, all committed Christians, all dying with an expressed faith in their ultimate resurrection at the last day, all having lived long lives and, although funerals are always shocking in the stark reality of death, there is a sense of rightness, of a circle now being complete. But what about the death of a baby? What can possibly be said which will be of any comfort, or solace or help to anyone. What meaning can be derived from such an event? "She blessed and gilded the lives of those around who knew her"? No she did not, her life has given me nothing but worry and unhappiness and misery and guilt. "She was a happy child and, although her life has been short, it has been blessed with happiness and joy"? No it has not, she has never even smiled in the short length of her life. Who could I possibly burden with such an impossible task of conducting the service? I think of all the members of my church (We Christadelphians have no clergy) Each person I call to mind would be unsuitable for the task for a different reason; too emotional; he would choke on his tears, too crass; he would upset everybody, too naïve; he would go wading in and miss the point. I decide to forget about the person

leading the service for now and instead choose a suitable bible reading. I sit back in my chair and stare at the ceiling. I have a good memory and I know my bible well. I can call to mind many passages from the bible that have informed, illustrated or illuminated situations for me. Now, however, I can think of not one single verse or chapter that would be helpful or suitable at such a time. I decide to forget about the bible reading for now and instead choose a suitable hymn. This is easy; a line from "Abide with me" has been haunting me. "Swift to its close ebbs out life's little day" What a little day it has turned out to be.

I make a deliberate conscious decision not to pray. I am not so much angry as disappointed that God seems so distant; send a trial, by all means, but where is the supporting strength? Where is the sign that it is a trial, and not just an act of spite, or perhaps even worse, a symptom of the fact that God doesn't have the power to affect what happens to his children? I am afraid of alerting God to the fact that there is a problem.Or perhaps he isn't really there after all.

I have been deeply affected all my life by an incident that happened when I was a child of perhaps 7 or 8 years old. A couple that were faithful members of our church, and close friends of my family, had a long awaited and much loved son, Sam. The child was welcomed into the church and passed around lovingly and joyfully after the Sunday services. Then Sam was suddenly taken ill and hospitalised. Naturally, prayers were said for the child and I remember our mother as she said goodnight to my sister and I telling us to say a prayer for Sam, which of course we did. However, Sam's condition worsened and so a formal prayer meeting was arranged at the church. I remember feeling relieved and confident when that had been done. Of course, now everything was going to be all right... "Ask whatever thou wilt in my name and it shall be granted unto thee." A week later the baby was dead. The sight of his poor mother's raw grief, and his faithful father's trembling upper lip has stayed with me, and I to this day cannot forget how that incident shook and challenged my faith which had, until then, been complete.

Now, this incident presents itself to me again. I don't want God, if he is there, to be involved, don't want him to notice us; if this is a test of faith, then He can forget it, I admit defeat, I don't want to be tested, just leave us alone.

By the end of the next day I feel if I do not have a night away from the hospital, I will probably collapse through exhaustion. As I drive away up the hill, I can see to my right the hospital lights shining brightly and clearly out into the night, like those of a great ship. I think of all the souls in that ship, some coming into the world and some leaving it, right there in the midst of all the varied teeming life of our town. Most people drive or walk past that hospital without even thinking about it. I myself have worked within its walls for day after month after year, chatted and laughed with my friends there, and not been aware really of what a place of transition it is. "Even in the midst of life we are in death" Now those words strike a special resonance in me, because the very lives of two people I love with all my heart are in that ship, rocking on the edge of the great abyss. What eternity lies at either side for those souls as the ship sails across the Styx?

As I sink into my own bed, I do not let my mind think about anything at all; I know that if I allow myself to think I will never sleep, and so I drink a large glass of whisky

and float off into oblivion. So deep is my sleep that I do not wake at all until after 7 the next morning. I had aimed to be at the hospital by then and so I dress in a frenzy and drive at top speed over to the hospital. I abandon the car in the car park and run into the building. I should have telephoned before I left the house to see how she was, but that would have meant even longer before I arrive back at her side. How could I do this to my baby? To leave her all night and then not to get back to her until after the new shift of nurses arrives, so I can't even talk to the nurse who has been looking after her in the time I have been away? What kind of mother am I?

I am running down endless faceless corridors, my feet pounding on the polished floors. I push doors open in front of me and pant up stairwells taking 2, 3 steps at a time. More corridors with their echoing starkness. All the while, screaming in my ears is the relentless piercing cry of an infant. I know the crying infant is mine and I cannot reach her, cannot provide for her, and cannot make the source of her distress go away. Running towards her with all my effort, all my strength and endeavour.

The crying becomes louder and more urgent as I approach Daisy's room. I push the heavy door open with my shoulder and the sight within sickens me; although I can hear her well enough, I cannot see her as nurses crowd the room. I feel to stand there for hours as, unnoticed. As I move closer to the cot I struggle to take in the scene. A senior nurse is trying to pass a nasogastric tube into Daisy's nose. This is obviously proving difficult and Daisy is distressed. However, the nurse carrying out the procedure is gossiping with the nurse standing closest to her. The other nurses in the room, presumably there to observe the procedure, are chatting amongst themselves. A little group of 3 or 4 nurses in the corner are sharing an apparently hilarious joke and burst out laughing as I watch. In the centre of all this, my baby; my beautiful, ill, helpless, only child is in distress, screaming and flailing her arms. I feel anger and fear well up inside me and rise to the surface. I try to shout but my voice trembles and falters. "What on earth is going on in here? Why are you laughing?" I glare at the group in the corner who look at me with surprise, but not guilt, on their faces. I turn from the room and run back along the corridors. I lock myself in the toilet and sit on the lid with my head in my hands, rocking, rocking, backwards and forwards.

When I return to the room all is calm. Daisy, now in a different babygro, is lying asleep, still but uncovered in the middle of her pristine metal cot, now with a plastic tube with one end disappearing into her nose and the other end taped to her cheek. She looks desperately ill; flesh barely covering her bones, her cheeks are sunken and her eyes are circled with a blackish tinge. Her skin is bluish. As I sit beside her I hear the familiar steps of auntie Sue on the corridor outside. I feel sick with fright for her; how will she react? What a shock she will have when she sees her. She greets me with a kiss before she looks at Daisy. She says nothing but her eyes fill with tears. I daren't meet them with my own. I must not cry, I must not, if I do it will let God, Fate, whoever, know that I admit defeat, make them notice me, try to bully me, see who gives in first. She tells me that my father-in-law had telephoned them very early in the morning. "I was terrified when I heard his voice" she admitted. "You know what I thought he was ringing to tell me don't you?" Of course I do, you thought Daisy was dead. I look down at my shoes, I can't even let the words, the possibility form into a coherent picture, or words in my head, and so in its place I hear a loud, high-pitched scream. I am still hearing the screaming but I can see that Auntie Sue is still speaking and try to make out the words. She is talking about Granddad, that he is

now having a different type of medication and has been moved into a side-room. I will go and see him later today.

It is Saturday afternoon. Peter and I are sitting in Daisy's room just as lunch is being cleared away, when Peter looks at the date on his watch "Do you realise it is Christmas Eve?" He asks. I leave the hospital and drive up to a local gallery I know which I have always found to be a rich seam of treats and presents, and with the added bonus of having a friendly and affable owner. "Aren't you going to have a wonderful Christmas this year!" she beams. I nod and smile weakly, too tired and full of tears to explain. I buy some presents for my delightful, healthy nephews and drive back to the hospital past twinkling Christmas tree lights, happy shoppers and excited children. The whole scenario of Christmas seems like a cruel joke.

I call in to check on Daisy and suggest we pop along to visit Granddad. As we approach the Ward I see that my sister-in-law and her husband are just leaving, and we smile as we approach them. The smiles disappear as we see their expressions; both have been crying. Through hugs and tears they tell us the news that the doctors have said that granddad is in heart failure and he will not recover. "I know we should just be grateful that we have had such an ace granddad," sobs Sam. My mouth drops open as I take in the scene in Granddad's hospital room. When I saw him yesterday he was the Granddad I have always felt so privileged to know and to share; smiling, laughing, positive, encouraging, laughing off his own troubles and treating everything as a huge joke. But will you look at him now? What do you see? Pale-faced but sweating, lying flat down in his bed, breathing noisily through his oxygen mask, hooked up to beeping monitors in his darkened hospital room. If he is aware that anyone else is in the room, he doesn't make it apparent. Grandma, practical and capable as ever, gets up from her chair and ushers Peter and I out of the room across the corridor into the relatives' room. "They've told us he'll not get better," she says. I look at Peter, His chin is trembling and tears are pouring from his eyes. I can feel a sob welling up and rising in me. Grandma stands up and puts her arms round us both. "Don't be upset" she smiles, "We have had such a good life together"

As long as anyone can remember, there has been a family party on Christmas Eve. This year, perhaps some might think surprisingly, is no exception. It doesn't seem inappropriate, though, Granddad loves his family above all else, and the only thing that possibly comes a close second, is a party. It is a wonderful, close family. There are ups and downs, like in any family, but any differences are usually quickly overlooked and, in such a time of crisis, naturally everyone wants to be together. "Party" is probably the wrong word, and it seems more like a sort of wake, but it seems right to be together. The silence is palpable as David; my poor, dear father-in-law says grace. He is the eldest son and must feel the burden as in a way he shoulders the grief for the whole family. But, characteristically controlled, his voice doesn't falter as he says the prayer for a blessing on the food and on the family. "Our hearts are tinged with sadness but we are full of gratitude tonight..." he prays.

Peter stays at the party, but I need to be beside Daisy, cannot bear to think of her alone on her first Christmas Eve, so I drive through the empty streets to the hospital. I call in to see Granddad, hoping against hope that I might find him a little improved, please God that the doctors might be wrongly pessimistic about his prognosis, but am sickened to find him more agitated, turning his head from side to side on the pillow,

huffing and puffing behind his oxygen mask. Grandma sits beside him, tenderly holding his arm. His youngest son and his partner smile to me in greeting. I stay for a few minutes then leave. I always balk at goodbyes.

When I reach the Children's Ward, Daisy seems much more settled and her eyes open briefly when I say her name. I lean into her cot and sing to her quietly, managing two lines of "away in a manger" before my voice cracks and the tears come. It is the first time I have cried in her room and I don't even care when I hear the door open and see the nursing sister enter the room. She shakes her head slowly whilst I tell her about Granddad. "What a time your family is having" She says.

I have settled into the pattern of spending a night at home and a night in hospital. Tonight, the night of Daisy's first Christmas, I spend at home. On the way home I call at a filling station for some petrol. There is jolly, Christmas banter between the young man serving, in his Father Christmas hat, and his customers. When my turn comes he looks at me and his manner and approach changes and becomes serious and matter-of fact. I wish him a happy Christmas and he reciprocates with his eyes cast down. The shop is silent as I walk out. I am far beyond caring about what anyone may think of me, but I wonder what it is about my manner that made my grief and despair so obvious to those people in the shop. I look at myself in the rear-view mirror of the car and realise why; my face is blotchy through crying and my eyes are like puffy red slits. I look and feel 100 years old.

Later that night, Peter and I lie side-by-side staring at the ceiling. I feel somehow that if I do not go to sleep but keep my eyes open all night then Daisy and Granddad will survive the night – if I do not sleep then neither will they succumb to the sleep of death. I mustn't go to sleep. The longer into the night I go without a phone call from the hospital, the more and more possible it will be that no souls will be taken tonight. Surely God will not take a precious soul on such a sacred night, when the air is so fortified by the buttress of prayers ascending from the earth below, and sanctified by singing angels above? But sleep must have come at last because the shrill, mocking reality of the sound of the telephone's ring pierces my soul. Peter leaps out of bed and sprints on piston legs down the stairs to the telephone. I stand beside him. He is nodding grimly and says "thank you" as he replaces the receiver. He falls sobbing into my arms. "Its Granddad, its Granddad. How could it happen on Christmas morning?"

When we get to the hospital Daisy's room is already full, this time with grieving relatives. My mother and father-in-law, and my sister-in-law and Andrew, her husband, are sitting in the room. They all get up as we come in and we hug and cry together. Miraculously, amazingly, Daisy's colour has returned and now, although she still looks ill, she looks just that, an ill baby who will get better, not the cadaverous form I saw lying there yesterday. Can it be that it has happened again? God required a soul and yet his wrath was deflected away from Daisy. Daisy, for some reason, some reason as yet unknown to me, has been preserved. God has spared her, and I didn't even ask for it this time. Maybe somebody else did, though. In all this uncertainty, one thing, however, is for sure, and that is that Christmas for our family can never ever be the same again.

Granddad was well known to the funeral director; as a popular lay-preacher in our church, he has himself conducted many funerals and so has had occasion to visit the funeral home many times when making arrangements. Grandma tells him the date of his death “Christmas day” she tells him with incredulity. “He loved Christmas so much can you believe he actually died on Christmas day?” “Of course,” replies the funeral director. “He was the loveliest, most Christian man I have ever known, it seems to me to be the most fitting day for him to be taken” I echo the words now. His influence on my life has been most profound. A true, living example of Christian values in action, always quick to excuse a fault in another, the first to laugh at himself, never heard to gossip maliciously or gloat at another’s misfortune, he laughed readily and cried readily. He was generous; generous with his time, with his home, with his possessions, with his forgiveness, with his love. He was the kindest man I have ever known, and his death leaves a gaping hole in the life of my family that can never be filled. The world seems a colder place without him in it.

After the funeral, walking away from Granddad’s grave, I notice the sickening sight of a small brown teddy bear on a small, new grave. I feel drawn to go over and look at the pathetic sight of a bedraggled poinsettia next to the teddy, with a hand-written label “To baby Angela Brooks, so briefly known, so dearly loved. Love from Mummy and Daddy x” Perhaps not so briefly known if things had been different, if we hadn’t swapped rooms, if I had not dared to make rash bargains with forces I know nothing about. What were the chances of that baby’s grave, in a town as big as ours, in a cemetery as sprawling as this, being across the path from granddad’s? And yet so many strange things have happened in the past few months that perhaps it is not so surprising after all. Here it is; now a double portion of sorrow for me to visit.

Chapter 12

At last Daisy is discharged from hospital. It comes as a surprise to me, although it is a pattern I come to recognise, that whilst I cope cheerfully and with strength in the face of the crisis, when the crisis comes to an end I crumple like a dry autumn leaf. I feel spent, exhausted and, although I have longed for this time, when it arrives I feel abandoned; thrown from the safety and control of the ship.

Following the advice of the medical staff, at nighttime I wrap Daisy in her outdoor coat and hat and strap her into her car seat, which is placed, beside my bed. The idea being that, maintaining an upright position will encourage Daisy’s milk to stay down and be digested. I find myself looking at the Laura Ashley catalogue’s nursery pages with their idyllic, cosy nurseries, presumably slept in by such lucky children cared for successfully by their proper mothers. I feel no jealousy or anger, but a flattening sense of failure, of being far outside the norm. Who else’s baby sleeps in her outdoor coat in her car seat? She looks as though she is in transition; not here to stay but just passing through my life... Increasingly I see her not as my baby to love, but as a condition that I must cope with and deal with, but not mine to keep.

I hope the official-looking handbook supplied by my health visitor may help me to see where I am going wrong, but I find that the differences I am experiencing are somehow fundamental, and the advice I find here seems so trivial; test the bathwater's not too hot, not too cold, have a cloth handy to mop up any posits of milk, not using too much soap as it may result in nappy rash.

Like an apparently unachievable syllabus, children's normal development is set out in a linear chart, covering all aspects of anticipated progress; reaching and grasping, sitting, crawling, babbling, uttering single words, drinking from a cup... I look at the little form lying on her sheepskin rug at my feet. I feel we are in a different category altogether. All these attainment targets are not applicable to us. Daisy will never, I am sure, achieve any of them. We are, in some way and for some reason, outside the camp.

Swallowing hard and glancing around the quiet room in the house, empty except for Daisy and myself, to check that no one is looking over my shoulder, I turn to the back of the book to look at the short chapter on babies with special needs, hoping for, what? Reassurance that my baby does not fall into any category dealt with here? An answer which will magically and effectively take away all my as yet deeply buried questions and terrors, a reassurance that my child and my parenting will eventually level out and catch up with everyone else's, perhaps. In spite of myself, I laugh when I read the words "Seek the advice and support of your health visitor"!

Because of the risk of infection, since Daisy's discharge from hospital we are advised to stay away from large groups of people so, as a consequence we haven't been to our church for some months. But now, spring is well on the way, Daisy has been kept on the strong antibiotics she was first given when an in-patient and so we feel the time is right to go to church as a family again. I sit in the library at the back of the church hall with Daisy, now 8 months old, lying on the floor beside me. I watch with utter disbelief at the scene in front of me. The boy, George, who had been born 2 weeks before Daisy, is sitting on his mother's knee looking at a picture book. As his mother, Julie, says the words, her son points with a chubby finger to the appropriate picture. "That's right!" Julie laughs, "and what noise does the sheep make?" I cannot believe my ears when George responds "Baa!" Tired of the activity, Julie plonks George down on the floor, where to my utter amazement he crawls off to investigate the toy box. I feel hot tears sting my eyes. I feel shocked. I can hear my heart pounding in my chest. I rummage around in my bag for nothing, so as to distract myself and hopefully anyone else who may have noticed I am upset. I manage to blink the tears away. When Daisy begins to cry, I wrap her in a blanket, strap her into the pushchair and push her away from the building with a sense of relief.

I need to get away, far away. The next day I drive to Haworth. It is cloudy and dull as I drive out of the touristy village and onto the road that leads to the moor. I park the car at the beginning of a wide footpath that leads up to the moors and eventually to the wild remote beauty of Top Withens. This is a special place for me, and I often take myself there at pivotal or difficult moments in my life.

I switch off the engine and watch the hillside to the right of me as the sun breaks though and chases the shadows off Oxenhope ridge. I love this view and at this time of year the air feels so full of promise, the countryside so fecund. I wind the window

down and feel the breeze on my face. It is not enough. I hadn't intended to walk on the moor, but now feel that I must. Daisy hates being in her pushchair and usually screams until she is sick when she is in it, so I wrap the little form in her blue blanket and stride out with her on the rough footpath. I walk for about a mile, silently carrying my burden, until we reach what is known as the Bronte waterfall. I sit on a flat plateau of soft grass and lay Daisy on the grass beside me. I lie back and prop myself up on my elbow to look at her. She looks like a little shorn lamb in her white babygro. Eyes watching the clouds above her she is silent but begins to kick her legs straight out in front of her with delight. At 7 months she still hasn't smiled, but I see in her eyes some faint expression of delight. On the path below us a man probably in his early 30s strides past in his walking boots. He waves and calls out a cheery "hello" to me. "Wonderful day isn't it!" "Yes" I reply, "it is a wonderful day" Propping myself up on my elbows I say softly to myself a poem of Charlotte Bronte's which I have known from childhood, having read it often from a little printed bookmark bought on one of our frequent visits to the dreary but evocative Haworth parsonage. Its words meant nothing to me at the time, but my mind had perhaps stored them for a time such as this:

Life, believe, is not a dream so dark as sages say,
Oft a little morning rain foretells a pleasant day.
Sometimes there are clouds of gloom,
But these are transient all:
If the shower will make the roses bloom
O Why lament its fall.

...Manfully, fearlessly
The day of trial bear,
For gloriously, victoriously,
Can courage quell despair!

The sun is bathing us, blessing us with its gentle spring warmth. My baby has survived the dark night. Maybe God, if He is there, has smiled on us. I look at Daisy manifestly enjoying the moment. The warmth, the breeze, the flitting clouds, perhaps the sound of my voice as the poem is spoken. For the first time in her life, I look at her in a new way; she is my daughter, she is not an illness or a condition, but she is my child. Could this be the beginning of something like the love mothers feel for their children?

I walk back to the car with Daisy in my arms. To an onlooker, the scene must have appeared most pedestrian; a woman carried a baby along the path to the waterfall, sat awhile, and then retraced her steps back along the path to her car. What the onlooker would not have seen was the invisible but monumental change that had begun to take place. The experience at the waterfall feels like a turning point. I had been plunging deeper and deeper, more and more out of control into a swirling and thundering abyss, thrown from side to side by terror of losing Daisy, terror of keeping her, guilt, anger, isolation imposed and self-imposed.

Nothing had changed but the experience of the last gift from Pandora's box; Hope. Hope that even in bad times the sun can come out and there can be shafts of warmth.

Although I would not have entertained the idea at the time, I believe that on that day God sent his Spirit, unsought by me, to sustain me, because He had not finished His work of changing me, albeit through painful experiences through which I am to be dragged, usually kicking and screaming.

The real Champagne moment, though, comes the very next day in my kitchen. My parents-in-law have called and Daisy is sitting opposite me on her grandmother's knee whilst we chat. I catch Daisy's eye and smile. To my utter astonishment her head wobbles with the gargantuan effort to establish some control, and then there spreads across her face the real sunshine of a lopsided grin. Just for me. This is it. This is the moment. I have fallen in love.

Chapter 13

It would be so marvellous, so neat, if the story were to end there, with a well, normal child smiling at her adoring mother, but the story does not end there, and during the time which follows life is punctuated, dominated still by fortnightly trips to the paediatric out patient clinic. There are many other admissions to hospital, too. Though none so dramatic and life changing as the first. They seem almost part of life; a cruel and often timely reminder that we are not by any means out of the woods. I begin to be ashamed to tell anyone when Daisy is admitted, afraid people will think I am so incredibly inadequate I cannot keep my baby well, that I need the constant support of the medics to enable her to cling to life, perhaps afraid too that they will tire of Daisy's constant illnesses and infections and think me a neurotic, panicky mother who cannot keep her child away from the hospital. I wonder what people do think. The subject of Daisy's illnesses and slow development is never ever commented on openly, and it begins to feel like the elephant in the room that nobody is talking about. I suppose everyone is waiting for my lead to demonstrate how the subject should be broached or dealt with, but I simply do not have the words to express my deeply buried anxieties about Daisy and her future; can't even express or admit them to myself. I worry that if I admit to people how often Daisy is ill, they will begin to suspect that I have the sickening and complicated Munchhausen's disease by proxy, where mothers will invent or, worse still, cause illness in their own children. The thought of this terrifies me; if anyone got that idea into their head, wheels could be set in motion which could result in Daisy being taken away from me, and it is mainly for this reason that I tell my health visitor that I have no further need of her services and ask her not to visit me any more. Amazingly, she concurs with my wish and I do not see a health visitor again for several years!

Sometimes closed questions or comments are expressed by family members following our regular hospital visits; "I bet Dr Dodds is really pleased with her isn't she" I picture in my mind Dr Dodds' worried, quiet concern. If I say "yes" I will give them what I think they are seeking; reassurance, permission to enjoy her babyhood, the pleasure of being right all along. If I say "I don't think he is, no" what will that bring? Questions I know no answers to. "Dr Dodds looks really worried about her progress" "Why? How do you know? What does he say? What is he worried about?" I honestly do not know the answers to any of these imagined questions myself. I just

know he looks worried and baffled. I'll say "yes". I'll find the words to talk about it all another time.

Apart from Daisy's frequent infections and poor general health, there is also concern about her failure to meet her developmental milestones. For example, most children are able to sit unsupported by the age of 6 or 7 months. Apparently the "cut-off point"; the point at which the doctors start to worry if a child is not sitting unsupported, is 9 months. At 16 months, when the majority of children are walking, Daisy simply does not have whatever is required to achieve the seemingly universally simple task of sitting. What is the required skill or ability that makes it possible to achieve this milestone which goes largely uncelebrated in the lives of most children? I dare not ask the question, but it seems that this ability, or rather the lack of it, is so significant in the mind of our paediatrician, as if the key to what the future may hold for Daisy is contained here in this facet of her development. What is it that she lacks which seems to make this function impossible for her? Is it balance? Muscle tone? Cognitive connection between body and brain? Part of me wants to ask, but a bigger part of me just doesn't want to know.

The babbling precursor to spoken language which babies develop and constantly build on, beginning with cooing noises from as early as 3 or 4 months, simply are not there from Daisy, who is either silent or crying.

The transition from taking only milk as nourishment, to being able to take solid food from a spoon is also delayed. At 15 or 16 months old I feel that, between us, we are just about getting the hang of how to give (and take) milk. I am shocked to hear from Dr Dodds during one hospital visit, that most babies are weaned by this stage, and that many are finger-feeding! How can this possibly be? It is not until I hear of the experiences of other families with babies of a similar age, that I realise how very different we are.

I deliberately avoid families with young children; to begin with Dr Dodds who strongly advised me to keep away from children who naturally pick up and pass on coughs and colds forced this upon me. I begin to do this for my own reasons, though; it is so painful for me to see children much younger than Daisy developing and demonstrating skills we are so far away from. It also hurts me to hear mothers doing what mothers always do – apparently boasting about their "top of the range" children. I now understand this stems from a natural delight mothers take in their blossoming; developing offspring, but to me the endless anecdotes of what little Henry said or ate or did rubs an incredible amount of salt in the wounds for me.

I am developing all kinds of conspiracy theories about my friends, family and even complete strangers. If people do not ask about Daisy they are heartless and do not care. If they do ask how she is or what she is doing they are nosey and accusing. I am an incredibly difficult, prickly person to be around.

I find people's response to our situation frustrating and unhelpful. Everyone has a story to tell me about someone who they know who had a baby who didn't sit at all; just stood up and walked and has now got a cupboard full of silver trophies for running the 200 metres, and so on and on. Someone even knew someone who knew someone who had a baby who never uttered a word until they were 5 years old and

then clearly announced that they “jolly well would if they wanted to”. I never know how to respond to the hundreds of stories like this that are related to me. Am I intended to stop worrying about my “toddler” who isn’t even sitting, never mind toddling? Because of some apocryphal story about someone else’s child? And don’t tell me not to worry; don’t dare to tell me not to worry. I am trying so hard not to worry. I hadn’t even told you I was worried anyway!

I hope that this has taught me an important lesson about supporting people who are dealing with, or trying to share a problem; we don’t want trite suggested solutions, it is more than likely that they have tried and exhausted more possible solutions than we with our incomplete knowledge of the situation have even thought of. We don’t want to be told to “think positive” or “not to worry” What is needed so often is just a listening, understanding ear. It is so hard to do this, but arrogant of us to think we have the answers to a problem which the sufferer themselves have not had the wit to think of for themselves. Sometimes there are no answers, no neat solutions. A most wonderful moment for me, in many ways a turning point on my road to accepting our situation, was when a very dear friend kindly said, with tears brimming in her eyes “Its hard for you isn’t it.” No questions or sticking plaster solutions or “don’t worry, it will all be alright” Just coming alongside me with understanding and acceptance.

Chapter 14

Whatever I do for Daisy, it isn’t enough, it doesn’t work. If she is awake, she is crying, wailing. She flings herself backwards and forwards in my arms if I try to hold her and goes purple and rigid if I try to put her down. She has been crying all day and I have longed for bedtime. Now night is here and it feels like the enemy. “In the morning I say Would God it were even, and at even I say Would God it were morning!”

I lie down on the carpet in Daisy’s room and contort my arm so that I can poke my hand through the bars of the cot. All I want to do is to lie down, although what I really want to do is to escape. I am weary of the task. After hours, hours like this, with what relief do I see the pale lightening of the sky in the gap between the curtains. We are sailing out of the evil night into the welcoming, peopled arms of the morning. But it is Sunday, my day of hostility and guilt. I feel bad if I go to church, bad if I don’t. Being there is such agony for me; the pretending I am all right, the small talk, the false cheerfulness. Besides, I am not on speaking terms with God.

So once again, I decide not to go. I am so tired my whole body is screaming. I slump down in a chair after lunch. Flicking through the Sunday Times I stumble on an article about the horrors of the death camps in Nazi Germany. It is not, I think, widely known or remembered that Jewish people were not the only people victimised and sent towards the unspeakable horrors of these heinous places, but amongst their numbers were anyone who was “different”; gypsies, Jehovah’s witnesses, people with disabilities or learning difficulties. Staring out at me from the newspaper is the sickening image of a naked little girl, standing against a measuring chart. She looks about Daisy’s age. She looks like Daisy. As soon as I see the picture I close the newspaper. I stare at the table. I feel sickened to the core. I can’t get the picture out

of my mind. I can't think about anything else. I sit at the table and rub my clenched fist back and forth across my forehead in deep distress, trying to expunge the image from my memory. Whose was the face the little girl was looking at behind the camera, who was it who pressed the camera shutter? What happened to that little girl who looked like Daisy, with those wide, puzzled eyes, after he had done so?

I think of those prophetic words again from Deuteronomy 28 which describe the situation for the victimised people in Nazi Germany so accurately " ...and thy life shall hang in doubt before thee, and thou shalt fear day and night and have no assurance of thy life: In the morning thou shalt say Would God it were even, and at even thou shalt say Would God it were morning" It seems there is no dignity in difference.

Chapter 15

I begin to feel I have two babies; one with problems, who is a problem, who is different, who gets lots of unwanted, unsought formal medical attention, and my own baby, who is just a normal baby, the baby I love when she and I are alone together, on those rare days when we don't have hospital appointments. When it is just Daisy and I we go for drives in the car. Her baby seat is strapped onto the passenger seat beside me. Daisy catches my eye and we grin at each other. That look is pure pleasure and mutual love. I sing "you are my sunshine" and Daisy stretches out her skinny little legs in front of her again and again in lieu of a laugh.

When we arrive at our destination on hospital visit days, though, Daisy morphs into the other baby I have, the one with the condition, the problem, the patient. I change too, from the person I am when it is just me and Daisy, to the person I am when other people are around, either people I know or people I have never even met; I feel as if they will think me callous and unfeeling if I am not upset and worried all the time, so that is what I become.

Besides the bread and butter paediatric appointments, there is ENT, occupational therapy, orthopaedics, paediatric genetics, and paediatric neurology. And physio, the dreaded, depression-inducing weekly visits to physio. I do not know what it is about these appointments that I find so depressing, but as I trudge into the dark Victorian hospital annexe I feel a sense of hopelessness descend. I sit for an age in the window-less, dimly lit waiting room and read the same copies of "Hello" magazine that I did last week and the week before that. Eventually the physiotherapist in her starched blue uniform collects us from the waiting room and leads us into the huge high-ceilinged room that presumably used to be a hospital ward.

She says things I am simply not ready to hear or even think, and which I have never heard from anyone else's lips "there may even be a remote possibility that she will become mobile in her own way at some point" "There are always things which can be done like the provision of mobility aids for Daisy" She beams at me and places a companionable hand on my shoulder, obviously thinking that her words have bestowed great comfort and hope upon me, but I feel once again the icy chill of the changeling world in my heart.

Every week it is the same; the physiotherapist spends a long time just watching Daisy as she lies on the mat and gazes around her, then Daisy's name is written in the appointment book for next week and I wave goodbye to the physiotherapist, balancing the wobbly Daisy on one hip and carrying my enormous bag of baby equipment on the other shoulder. As I leave the building I feel a sob building and rising from the pit of my stomach. My eyes swim with tears but I keep it all contained whilst I am in the car, out of sight. I strap Daisy into the seat and stow my bag in the back. I collapse into the drivers seat and close the door, and then I allow myself release and lean over the steering wheel as the tears flow.

Each Thursday, before we reach the hospital, I plan to do something afterwards to cheer myself up, sometimes lunch in a café, or a walk on the moors if the weather is nice. On this particular Thursday, after another hopeless and seemingly pointless session, I have planned a trip into town to buy material to make some curtains for Daisy's room. As I walk along the street I pass a woman dragging a child about Daisy's age by the arm. The child is obviously not walking fast enough and the mother stops, bends down to the child and shouts in her face, jolting her by the shoulder as she does so. The sight sickens me. Blessed with a normal child, how can she waste the experience and the miracle like this? How can she not bubble over with joy that her child has survived the journey of gestation and birth? How can she not cherish and enjoy the precious gift of her child. Where does she need to get to so urgently that it is more important than loving and laughing with her beautiful, healthy child? With an effort I restrain myself from shouting at her, to love and appreciate the riches that are hers and not mine.

Nobody speaks about our weekly visits to the paediatric clinic and although I am desperate to talk about the visits to unburden my experience, where should I begin? Still nothing is said of any definitive importance, just endless measuring of height, weight and head circumference, then Dr Dodds looking worried whilst he studies the centile chart, stroking his beard, scratching his head. Sometimes I feel that after a particularly long silence I have to say something; "What are you thinking?" I ask. Another long silence. "I am wondering if there is something about her which means that she can't grow" So many questions and feelings crowd into my head – does that mean she will always stay a baby? What about in 2, 5, 10 years' time – will she look exactly like she does now? But will she develop intellectually? Will she sit her GCSEs in her baby grow, looking like a baby? Surely all this is impossible. I think of the bible verse "a child shall die at 100 years old" There are so many questions I want to ask but I am so shocked that I can form no coherent sentences and I simply do not know what to say, where to start, so I don't say anything and neither does Dr Dodds, apart from "See you next week" and the week after that, and the week after that.

When Peter returns home from work he is quiet. "I went to see Dr Dodds today" I offer. The responses vary from week to week. Sometimes the response is that there is no response. Sometimes the loaded "and what did he have to say for himself" I find this a difficult question to answer in such an apparently hostile environment. I know

that whatever I say I will be in trouble. “Nothing specific, but he looks worried” “What is he worried about?” “Well I don’t really know he didn’t actually say” “Well why didn’t you ask? What a waste of time! I don’t know why you bother taking her if he’s not going to bother saying anything and you aren’t going to bother asking any questions...” Sometimes, on clinic days Peter will come home, change out of his suit into jeans and a t-shirt and then disappear down the lane, presumably for a walk, slamming the door behind him. There is so much to say, to share, but nothing to tell. I feel a chasm widening around me in every direction, between me and other mums, between me and my dreams and expectations of how life was going to be, between me and my church, me and my friends, me and my family, me and God and now between me and my husband. I withdraw further and become silent.

Peter seizes the TV remote and looks at me. “So what if she’s not walking as early as some children? Everybody walks eventually, everybody can walk. How many adults do you know who can’t walk? So what does it matter at what age they started to walk? It doesn’t matter if she did it last month or does it this month or next month does it?” He looks at me accusingly and waits for an answer. When I offer none he switches on the TV and withdraws from our world of poor communication into the banal wordless world of sport. I retreat into the kitchen and as I stare out of the window whilst washing the dishes I think of all the children I see in the clinic waiting room, rocking in their little wheelchairs, children who won’t walk this month, next month, or ever.

Chapter ?

Shoes

Baby’s first shoes

A milestone;

The first milestone marking the miles and miles these little feet have yet to walk.

What shall we choose?

Pink for the girly girl, party girl, ribbons and bows girl?

Blue patent shoes for the smart girl, shopping girl, walking to the park girl.

Lots to choose from, trotting round the shoe shop, looking in the mirrors,

Curtseying low.

Leaving the shop with a pretty green shoe box, miles and miles to go

I struggle to hold Daisy still whilst the physiotherapist takes a template of Daisy foot. “The boots will take about 4 weeks to arrive” she tells me, trying to make herself heard over Daisy’s screaming. “They will need to come up quite high to support the ankle, to try to encourage it into a more normal shape” I will myself not to show that I am upset. It is no big deal, we are only talking about a pair of shoes. But the development seems pivotal, significant, a rite of passage in a pair of shoes.

“There’s not much choice in colour, I am afraid” confesses the physiotherapist, her pen hovering over the form marked “Hospital Appliances” “Would you like brown or white?”

“She should wear them for a couple of hours at least every day” I am told. “If she isn’t wearing them, she should have bare feet or socks, but not commercially bought shoes for the foreseeable future”

When the boots arrive they are stiff, high, clumpy lace-ups, conspicuously inappropriate for the hot summer it has become. “They are lovely, beautifully made, they would cost a fortune to buy. You are so lucky!” A tactless friend, trying to be tactful, tells me. I don’t feel very lucky. I just want to buy my lovely little girl some lovely little shoes.

Chapter 16

There is a Jewish joke that goes like this “A rabbi was marooned in a flood on the roof of his synagogue. First a lifesaver swam towards him, but passed him by because the rabbi gave no signal, for God would find him in His own time. Then a lifeboat also passed by, but the rabbi meditated on in silence. The flood waters rose higher and then the rabbi prayed. “ I wait patiently for your salvation, Lord, how long?” A voice came from heaven. “I’ve already sent my salvation twice, you blithering idiot, and you sent it back both times.”

This story has certain parallels with me, but is not a perfect fit, because I suppose I know in my heart of hearts that God is reaching out to me, but I am so angry I am choosing not to speak to him! Like a stroppy adolescent who is outraged and frustrated by her parents, I slam down the shutter on communication each time. If He has the power to send support, how come He hasn’t the power to make Daisy healthy and normal, to make all the other children I see at the hospital healthy and normal, to have protected baby Angela? My heart is closed, my arms are folded, and I will not listen.

Nevertheless, I know that God is stretching out His hand to me, in spite of my anger. Although I have withdrawn from Him, He seems reluctant to withdraw from me. Like the vision of Ezekiel, in which God’s glory leaves the temple in Jerusalem, just prior to the exile of the Jewish people to Babylon. In Ezekiel’s vision, God’s shining, warming, protecting presence is reluctant to leave, and hesitates as it moves, in stages, sadly away.

God, against my wishes, and unsought by me, sends individuals to try and support me, reach out to me.

Daisy is ill again. She is floppy and listless. I know by looking at her face that she has lost weight. She has not the strength to take any solid food so I retreat back to the breast milk. She takes a little but the effort is obviously too much for her and she loses interest. I warm a bottle of formula that she won’t take either. In desperation I take a pair of scissors and cut two slits in the teat of the bottle, forming a cross. I tip

the bottle up and the milk just pours out. She cannot fail to take it. She does not even have to suck. I prop Daisy against the crook of my arm and coax her lips open so that I can slide the teat between them. A little of the milk pours in. I withdraw the bottle but sit perfectly still. Even if she brings the milk back, presumably the longer I sit here, the more chance there is of at least a little of the milk being absorbed. I daren't move. I just sit still. I can hear the ticking of the clock. I can feel my shoulders tense and pins and needles stab my arm, but still I do not move. I have noticed that if Daisy is going to bring milk back she makes a tiny clicking sound which seems to come from the top of her oesophagus. If I hear that click the milk will come back. It may be 5 or even 10 minutes later, but it will come back. I listen for the noise, but hear nothing. The milk stays down. Feeding Daisy is like playing whist. Do I stick or twist? If a little stays down, that is better than her bringing the whole lot back, but maybe she could take a little more? If she does she will stay alive a little longer. Every feed has life or death consequences. I will twist. Without shifting in my seat I prise Daisy's lips open just enough to slide the teat between. I hear her swallow and I withdraw the teat. I daren't move. I just sit still. I can hear the ticking of the clock. I can feel my shoulders tense and pins and needles stab my arm. I hear a tiny clicking sound from Daisy's throat. I grab the towelling nappy from the table beside me just in time as the dull cream liquid shoots from Daisy's mouth and nose. She collapses exhausted against me and I dab the milk from her little pink towelling baby grow. It seems cruel to disturb her by pulling her about and changing her clothes so I put a towel around her and put her in her little rocking cradle by the radiator in the dining room to sleep.

I sit with my head in my hands at the kitchen table wondering how I will get through the day. I long for tea time when Peter will come home, thinking everything will be better when I have his support and I am not alone, but every day I feel so disappointed and sad that we don't support each other at all, and are growing more and more hostile and distant.

My gloomy cogitations are pierced by the sound of the doorbell. Standing on the doorstep is a short, grey-haired man with a wide friendly smile. "Hello" He holds out his hand to me. "I am from the church up the road. Can you spare a minute?"

Ten minutes later, both holding mugs of steaming tea he is explaining to me that he is distributing "prayer request cards" "They can be anonymous" he reassures me, or you can write your name and address on the bottom if you would rather, and then you write on the card something you would like us to pray about, or someone could come to you and pray with you at home, if you have anything you feel you would like to pray about." He pauses and smiles at me. "Is there anything you would like to pray about?" His bright blue eyes look straight into mine. I can feel my own fill with tears and I look quickly away. I jump up and go to the sink and dribble water into the kettle. "How about a top-up?" I ask cheerfully "I think I have some biscuits somewhere if I can tempt you?"

We chat about village happenings; the little shop at the bottom of the road is about to close because it can't compete with supermarket prices and choice, new people have moved into the big house on the corner, and so on. I wonder if it is obvious to him that I am being evasive? Perhaps he thinks I am not religious and so don't want to be involved with his prayer group idea.

Tears stream down my face when he has left. I look at the little yellow “prayer card” he has left with me “in case I think of anything” Why don’t I fill it in? Partly because I am so angry with God that I don’t want anything to do with him, partly because I don’t believe he is there in the first place, but mostly because I do not have the words to express even to myself what I am feeling deep within myself. I know that Daisy seems to be different from other children, but this has never even been discussed with anybody in an open forum, she is certainly nowhere near receiving any kind of diagnosis or explanation for her difference, and still all my family are telling me that everything is going to be alright, and not to worry. I am afraid that if I try to put any of my feelings into words, a dam will break and I honestly do not know what would happen; maybe I will begin to cry and find I am never able to stop. Years later I still have the little yellow card, still blank.

The following week, just after I have put Daisy to bed, the doorbell rings and, standing on the doorstep is the slightly nervous-looking figure of our old friend from church, David. Peter and I have been privileged to know David since our teenage years. He shifts uneasily on his chair and I wonder what on earth he has come to say as it becomes apparent that this is not merely a social call. He clears his throat. “We are worried about you. You are not happy are you?” I am so touched by him taking the time and trouble to visit, and by his brave approach. I fuss around offering and making tea and toast and we sit amidst the debris of a day spent with a young child. I try to avoid the subject but he is determined. “Why don’t you bring her to church so that we can all enjoy her?” I am taken aback by the words. The idea that anyone could enjoy her surprises me. I have been thinking a lot about the church and the wider world we live in. Everything seems to be so rigid. Of course there are individuals, characters, eccentrics even, but they all fit into the broad brackets of normality. They can all walk, they can all talk, and they can all read and write. What if somebody is outside those brackets? Take our church life, for example, it is assumed that all worshipers conform to certain standards and beliefs. We spend a lot of time sitting, listening and understanding. What if Daisy cannot do any of those things? Can she truly be a Christian if she doesn’t have the mental capacity to follow, understand and embrace quite complex ideas? If she cannot, does that mean that she is outside the scope of God’s grace and love? If that is the case, where does that leave me? Do I really want to be a part of that church, that exclusive system? Do I want to be part of a system that would exclude my daughter? What kind of God would stipulate that a person had to understand certain truths in order to please him, and then make a person who was, by their very nature, unable to understand anything? A vindictive God? A God enjoying a cruel joke, or no God at all, like the Wizard of Oz?

My voice wavers as I try to explain to David the real reason why I have not been bringing her along to church. The words are difficult for me to say. “There is no place there for anyone who is different” I cannot believe I have said the words. A simple sentence has summed up all my terrors. The silence in the room waits for David’s response. I expect to hear the exhausting “She will be fine, don’t worry” but instead I hear David sadly say, “oh please don’t ever think that” I feel comforted by the words. The system may be rigid, but perhaps individuals within it are not so rigid as I thought. I still don’t take her to church though. The person I was when I went into hospital in labour that September night emerged as a completely different person. The safe, cosy world I used to inhabit was left far behind when I sailed off into the

night in that good ship. I find I know nothing about this new place. It feels strange that superficially everything looks the same, but everything has changed, and now it is an alien place. An idea from Keats expresses perfectly how I feel; "...the sad heart of Ruth, when, sick for home, she stood in tears amid the alien corn;" I feel I am so far from home, far from familiar safety, where everything was sure and certain, black and white. Now I stand, like the biblical character of Ruth, amid the alien corn of faithless insecurity. Yet I know that in all this God is somehow stretching out his hand to me still.

I train to join the Samaritans. Behind the story I tell myself about helping others in dire distress, the real reason I go through the gruelling training is that I hope someone will help me find a way to let me open up. I am like an abscess rotting and festering. I have not the means to lance it. Many people ringing the Samaritans are much more together and able to cope than I am myself.

Chapter 17

"Any speech coming?" Dr Dodds asks at one of our frequent hospital appointments. I admit there isn't, not even baby babbling. At age three and a half I know this is significant. It doesn't seem odd to me, though. Daisy and I have developed a special relationship that doesn't need words for communication. We have never had them, so we don't miss them, especially now we have stopped looking for them, longing for them. Life seems so much easier when you just relax into it, don't hope for it to be any different or better than it is now. If it does get better, that's really great, but if it doesn't that's great too. I understand that this perspective must seem dangerously close to giving up, but it makes the present so much more enjoyable.

"Do we know that she can hear? Have we ever had her ears properly checked out?" wonders Dr Dodds. When I say that we haven't he reaches into his letter rack for a referral card. The appointment card drops onto the letterbox after a day or two. 24th December. Christmas Eve. I hear about children with common childhood ear complaints and talk of glue-ear and grommets. Daisy has had more than her fair share of colds. Perhaps her ears could have got a bit bunged up? I wonder how much time, if it were all totted up, have we spent in waiting rooms since Daisy was born? It probably amounts to days on end! But this is a new one. ENT. I flick through a different set of dog-eared women's magazines, looking at who wore what to this or that celebrity dinner. Who could possibly care? I am showing Daisy the ENT notice board when Daisy's name is called. A plumpish lady in a greying "white" coat beckons us into a windowless room. She has a harsh-looking face and does not smile or engage in any small talk. She addresses Daisy; "I am going to put these headphones on you and I want you to tap on the desk when you hear a noise..." The idea that Daisy would be able to understand the complicated instruction, let alone carry out the task is completely unrealistic. "Er, I think that might be asking a bit much of Daisy" I volunteer. "Is there another method you could use that doesn't need Daisy to respond accurately?" The audiometrist gives me a withering look for apparently messing up her assessment. Daisy obviously takes a bit of a dislike to the lady's abrupt manner and her eyes brim with tears as the lady approaches with metal implement. "Don't worry, she's not going to hurt you" I hold Daisy close to me.

“Don’t tell her that” snaps the audiometrist. “It annoys me so much when mothers say that to their children when they are about to have a procedure done” I move Daisy away slightly. “Is it going to hurt?” I ask. If it is then she can forget it. “No, but she doesn’t know that” She puts the little metal probe into the protesting Daisy’s left ear, then the right then, after a bit of fiddling around on the computer, prints out a long strip of paper. She looks at it and then turns to me. I simply cannot believe the words that come out of her mouth, with no preamble, no consultation with anyone, no softeners. “I’m afraid the reading shows that your child is profoundly deaf” I look at her. I look at Daisy, now screaming on my knee. I look back at her. I don’t know what to say. “There is nobody else in the Department now, everyone has gone home early and we’re closed now until the new year, so I can’t make you an appointment to see the ENT Consultant, so I want you just to forget all about it until the new year, and have a nice Christmas.”

Forget all about it? Forget all about it? How on earth can I forget all about it? I had thought I was just about getting to grips with the Daisy I thought I had. Now it seems I have someone completely different; a child who is profoundly deaf. Just about the only thing I thought I knew for sure was working properly was Daisy’s ears, now it seems that even they are not! I feel I am spinning around in a centrifuge. When Peter comes home from work I tell him what has happened this afternoon. He is angry. “Of course she can hear! She turns and looks at you when you talk to her. Why would she do that if she couldn’t hear?” It is baffling, but I saw the machine printouts with my own eyes. The readings should have shown steep peaks as the eardrum moved in response to sound. Instead of that I saw two long, flat, unfluctuating lines. What can’t speak can’t lie.

The Christmas break between ENT appointments gives me time to think about this new situation. Perhaps it is good news after all. If Daisy can’t hear, that would go a long way to explaining her problems. Perhaps her early illnesses were the cause of her problems, damaging her ears in some way. Of course no speech would develop if the poor child has never been able to hear any. In many ways a diagnosis would be lovely; would make everything so much easier; no more working in a fog of pretending and not knowing. I know one or two people in the deaf community and it is just that; a wonderful, close community. Deaf typically shun the word “disabled” Sign language is a beautiful, expressive form of language, just as eloquent and accessible as spoken language is to hearing people. To be part of that world would be fine by me. I hadn’t realised until now what a strain having a problem but not a diagnosis had been. To belong to a community; be it Downs, deaf, whatever, identifies one as part of a group, gives a degree of closure so that the individuals concerned can work with it and move on in a positive way. It will be very different from the life I would have chosen for Daisy, but it can be a good life.

By the time our appointment arrives, I am almost fully reconciled to the idea of Daisy being hearing impaired. As we wait in the ENT waiting room once again, I show Daisy the colourful Christmas decorations around the room. This will be a great adventure. I feel so positive. It is not like the old days when hearing-impaired children are sent away to school, forbidden to sign. The whole family can learn sign language and Daisy will at last be able to communicate with ease. Daisy will cry less and less, feeling less frustrated because that she will be able to make her wants and needs understood.

Daisy and I are shown into the consulting room to see the ENT surgeon. He reads Daisy's hospital notes then struggles to look in Daisy's ears whilst she wriggles and squeals on my knee. "There is probably a bit of glue-ear going on there..." he mutters, almost to himself. "She's already on antibiotics isn't she?" he addresses his question not to me, but to the nurse, who nods. "Maybe we could piggyback some others to shift that" He flops down into his chair and looks at me for the first time. "A little bit of glue ear but nothing we can't shift" He smiles encouragingly. I don't know what to say, what to think... "But what about the audiometry report?" He flicks through Daisy's notes until he finds the report. "Hmmm, they are a bit flat aren't they, but that's not the only thing to take into consideration. Take this prescription and make an appointment for a month's time" He hands me a piece of paper. "So she's not deaf?" I ask. "What? Oh no, should be able to clear up that little bit of wax in no time" He lifts up his right hand to me whilst taking the next patient's set of case notes in his left. The gesture means, "I have spoken. The consultation is over. Goodbye"

I realise that most people would be feeling elated that their child had been misdiagnosed and wasn't profoundly deaf after all. My disappointment is unreal, hard to understand, even for myself. It felt like the end of all the uncertainty, all the difficult, half-formed questions. So far, all I have had are unanswered half questions; at last I had something definite. Now even that has been taken away. A diagnosis of deafness, I am sure would be devastating to the majority of parents, and would perhaps be seen as a tragedy, but I had come to think it would be a solution, rather than a problem, to us. It would have been such a clear explanation for Daisy's slow-development and lack of speech. It would have been so lovely to know what sort of child I had, to be allowed into her world, to be able at last to help her. It would be like getting on a boat and travelling out across the sea, rather than flailing around in the water, tossed about by every wave that comes along.

I strap Daisy into the buggy and push her along the road in the frosty winter sunshine to the bookshop café. A cup of tea in the café will be a treat and help me get my head together. We are the only customers in the café and I sit with Daisy at my knee looking through the window, watching the passing cars. The tea and scone I have ordered is ages in coming and Daisy is starting to get restless on my knee. She screams and throws herself around, and bangs my lip with her head. She cries out in pain and I try in vain to comfort her. I feel like crying myself as I wipe the blood from my lip with my cuff. I stand up and try to distract Daisy by rocking her. By the time the waitress brings my tea and scone Daisy is wailing. Of course Daisy must be tired, she will be asleep, I know, within a few minutes of the car engine starting up. I take a bite from the scone, wash it down with a gulp of scalding tea and clumsily manoeuvre the empty pushchair out of the shop, the weeping Daisy under my arm.

When Peter gets home after work he doesn't even ask about the appointment. I feel so angry about this wall of silence between us; meaningful communication has broken down completely between us. We hardly ever talk about Daisy's development. On the rare occasions that we do we quickly end up falling out. We have become reluctant job-share partners. I brace myself what will surely be another battle. "It was the ENT appointment today," I offer. Peter continues to look at his post; letter in one hand, envelope in the other. After what I consider to be too long, he stops

looking at the letter and looks at me. I feel my temperature rising, but try to keep my voice calm. I wait for him to ask about the appointment, but he just looks at me. “He doesn’t think she’s deaf, he thinks she has glue-ear” “Well I could have told you that. Of course she’s not deaf, anybody can see she’s not deaf” The telephone’s bell cuts across our rising tempers. As Peter greets the caller I turn back to the stove. It’s like living with a stranger.

Chapter ?

We have been referred to a Paediatric Neurologist at Manchester Children’s Hospital. I have lost count of the number of hospital departments we are known to. Daisy’s hospital notes are so extensive they have outgrown their buff-coloured manilla folder and now occupy two volumes; What hospital medical records staff call “fatties” It seems ironic; it is the only thing about Daisy that could seriously be described as “fatty”.

We sit down in the unfamiliar waiting room and I glance around at the other families. All have a story to tell, some look exhausted, some look angry, some look hopeful, some look resigned. I wonder how we look. Beside me sits a woman, probably in her early 30’s, with her apparently autistic son. She tries in vain to keep him under some sort of control whilst he noisily empties out the toy box and throws the toys, one by one, across the room. I have brought a pile of Daisy’s favourite picture books and she lolls on my knee whilst I read the familiar stories and talk about the pictures. The door into the waiting room suddenly bursts open and an extremely angry-looking nurse approaches the woman sitting beside me. There is a hush in the waiting room as the nurse noisily and publicly upbraids the mortified woman. “You don’t have an appointment to see the consultant today because you failed to attend last time. If you fail to attend without letting us know you have to be re-referred by your GP. We don’t just keep making appointments if you’re not bothered” The nurse is so angry that she is red in the face. Her anger appears disproportionate to the crime. She towers over the woman who first tries to apologise, then explain, then quietly drops her shoulders and begins to weep. The nurse retreats, leaving the woman with her head in her hands, sobbing quietly. Her young son leaves his toys and looks, bewildered, into his mother’s tear-stained face.

I place my hand on the woman’s arm. “Excuse me” I falter, “Would you like a cup of coffee?” “No thanks” she replies, “I’m ok” The nurse, embarrassed by the woman’s tears, perhaps ashamed now of her own angry, bullying tone, tells the woman she will do what she can and try to arrange for her son to be seen after all. I cannot bear to witness the woman’s hopeless tears without trying to do something, so I scoop Daisy up under my arm and go to the drinks machine to get two cups of dishwasher coffee.

When I return to the waiting room, the nurse has left. The woman has stopped crying and is blowing her nose. “I brought you a cup anyway” I hold out the cup; an offering of solidarity, of fellowship. As she takes it her eyes fill with tears again. “I just forgot.” “We have so many appointments in different departments I can’t keep track of them all. I never have more than a couple of hours sleep a night and then Alex is up shouting and trashing his room. It was when she said I couldn’t be bothered I cracked. I have to do this 24/7. How can anybody think I’m not bothered?”

The incident struck a chord with all of us in that waiting-room, I think. Although nobody spoke, as I glance around I notice, through my own tears, that there was not a dry eye in the house.

Chapter 18

I have a friend who works at the hospital as a consultant. He has known Daisy all her short life and I ask him cautiously what I think might be her trouble, what makes her as she is. It is just before the days of the Internet, where information is so readily available to anyone who cares to look. I ask my friend to go to the medical library and look through the books and journals, and to photocopy details and descriptions of any condition he thinks could be relevant, and to post them out to me. Two or three days later a large envelope drops onto the doormat. I stare in disbelief at page after page of pictures and descriptions, many of which would fit Daisy perfectly. The descriptions put into stark black and white what has been an emerging, developing, unspoken truth for years; Early delivery, poor feeding due to poor muscle tone and primitively formed facial muscles, recessive chin, delayed motor milestones, retarded language development.Most striking of all, though, are the photographs; staring at me are dozens of photographs, many of which one could believe were photographs of Daisy. The junior doctor who had, so cruelly it seemed to me, written "baby slightly odd-looking" turned out to be right! Although undeniably indelicately put, all these babies and children, all looking startlingly like my Daisy, could all be described as "slightly odd looking"

I feel incredibly guilty looking at this information. It feels as if I am betraying Daisy. I am compelled to read this information because I am sick and tired of not knowing, of wondering, of hiding, of being in the dark. I have to find out why Daisy is different from other children. But in saying this, I feel as though I am saying that Daisy is not good enough for me, that I am disappointed with her, that she is not what I was hoping for when I wanted a family of my own. I hurriedly put all the papers into a folder and stash them away in my workbag. I will hide them away. Nobody will ever look there. I can go on pretending for a little while longer, forever maybe.

Saturday morning. It is a cold, rainy spring morning. It is Peter's turn to get up with Daisy. I turn over when I hear her cry and try to go back to sleep. I last another 40 minutes listening to the traffic accelerating up the steep hill outside my bedroom window. No sleep comes so I get up and go downstairs. My heart misses a beat when I look on the kitchen worktop, for there, exposed for all to see is the pile of photocopied papers sent from the hospital. The rest of my bag, other contents spilled over the kitchen floor, evidently having slipped off the worktop.

I don't know what to say. I feel as if I have been having an affair, as if I have been storing up deceit after deceit, not being open about my fears and my discoveries. Communication between Peter and myself has become so difficult, such a contention, that I have simply given up. I drop down onto the cold tiled floor in front of Peter and sob. It is the day of the storm. Outside the heavy clouds have been gathering for days. Inside, the heavy clouds have been gathering for years. There is crashing, shouting, hot, angry, mourning tears. Blame. Guilt. Transition.

We get into the car and drive to Hardcastle Craggs. The ground is slippery with surface water, but the air is clearer, so much clearer. We laugh and cry and hold hands as we push Daisy along to the pond where we can feed the ducks.

A few weeks later, Peter and I sit down and watch the film “Edward Scissorhands” which is about a boy who, instead of having normal hands, has sharp scything blades in their place. The film is about how people in his community, after first enjoying and celebrating his difference, suddenly turn against him and victimise him in the most horrible way. At the end of the film, to my surprise, Peter collapses into my lap, and sobs loud, angry tears. “I am so terrified of the future; how will people react to Daisy? How will they treat her?”

There have always been people like Daisy, and always will be, I suppose. The way society reacts to them is the variable, though. Not so many years ago, society responded by shutting them away, to be “cared for” by nurses in starched uniforms, in mental hospitals, institutions and “homes” It has always struck me that “a home” is a place as far removed from the characteristics of a true home as it is possible to be; When is a home not a home? When it’s a Home! Disability, or difference, like childbirth and death, had been mediatised; removed from ordinary people’s lives, making ordinary people feel out of their depth in the presence of such life states. That difference is acceptable, and to be welcomed and embraced even is, I think, I hope, a view that is becoming more widespread.

Chapter 19

Driving home from the supermarket one day, I read again a sign outside the village hall. It is a sign I have seen out of my eye corner many times, but never thought about it as being relevant to myself. The sign reads, “Pre-school Playgroup held here Mon, Wed, Fri mornings in term time. All Welcome” The sign is painted in child-friendly bold bright colours and a clown holding balloons is depicted in the corner. How about it? Each time I pass the church hall I read the sign again. “All welcome”. Daisy has been on antibiotics for a year or two now and her constitution seems more robust. Although she has frequent coughs and colds she doesn’t have illnesses of sufficient severity to land her in hospital on a drip. Perhaps it is time to move on to the next stage. The possibility excites and cheers me. Daisy could at last begin to socialise with other children. I could meet other mums. The wider spin-offs of being a member of such a group present themselves – Daisy’s friends playing in the garden, staying for tea.

I jot down the contact number and arrange our first visit. The matronly-sounding voice tells me that now would be a great time to start, as a number of children have recently left playgroup to attend school. “Why not come for a visit tomorrow?” Why not indeed? This will be a turning point for us. It has been a bad start, an awful start in fact, but things will be different from now on. It has been such a long hard winter, but winter seems to be receding now and spring is awakening.

The day of our first visit is fine and clear, so I strap Daisy into the pushchair and walk briskly along the wooded lane between our village and the next. The trees that line the lane reach down their branches in the breeze, encouraging us on our way to our new adventure. I lift Daisy from her pushchair and lay her on the floor as I manipulate her out of her snowsuit. Balancing her on my hip, I push open the heavy door of the echoey village hall with my shoulder.

I am not sure what I expected to see exactly. I have spent such a long time cocooned in my own little world that I have lost touch completely with what other children are doing, what stage they have reached. The room is filled with the noisy, happy chatter of adults and children, squealing and shouting, as boisterous youngsters race around the polished wooded floor on little trikes and scooters. I swallow hard and blink back the tears as I prop Daisy on the floor against my leg so that she doesn't wobble over, and bring a couple of her favourite toys out of my bag, which she turns over and over in her hands.

Who am I trying to kid? We have no place here; we are worlds away from this everyday experience of normality. As I sit and watch the children playing, it is like gazing through the window into a world I can see but can't touch, can never be a part of.

At the end of the session a playgroup leader brings me an admission form for me to take away and complete. She goes through it with me and I nod and smile obligingly, but I know then that I have no intention at all of coming here again. The form, which sits between us, may as well be a reinforced concrete barrier. There is a tiny box headed "Medical History" giving enough space for about two short sentences. Even if I had been provided with two pages to go at, where would I possibly begin? Even if I could countenance filling in this form, There would be no way Daisy could go to playgroup; she is not mobile, not even crawling, she has no speech whatsoever and she is still in nappies.

My head is in turmoil as I push the weeping Daisy back along the tree-lined lane. The breeze has dropped and the trees lean towards me and listen for my response to the morning's events. And yet I have no response, no body seems to have a response. How can we be so, so different, and yet there is no problem, all any one says is "don't worry, she will be fine" There is no mention of a reason, a diagnosis. Nothing is wrong but everything is wrong. Home at last. I close the front door behind us and leave Daisy asleep in her pushchair in the porch whilst I go into the warm kitchen and make a cup of tea. When we are here, just Daisy, and me there is no problem. Everything is normal. It is only when we go out there that the problems begin.

Chapter 20

The word "delayed" is the latest buzzword in the medical world I inhabit. I come to think it is a misleading term, offering false hope, an unclear message. "Delayed language" "Delayed motor skills" "Delayed cognitive development" It is misleading because if something is delayed, the expectation is that whatever, or whoever is involved will catch up. If a train is delayed, it doesn't mean it is cancelled, or that it

wasn't there in the first place, it just means that it is delayed. It is still scheduled to come along the same track; it is just that it will take a little longer to arrive.

I see a poster in the hospital waiting room advertising an 8-week language programme for families with a child with "Delayed language" I feel I must do something, anything to positively help Daisy, for us to reach forwards in some way. The language programme, however, held each Thursday evening at the local hospital, is of no use to me. All the other parents attending the course do, indeed, seem to have children with "delayed language" not no language at all, as in Daisy's case. "His language seems to babyish compared to his friends," complains one mum. "He says things like "Me go for a bath now". If Daisy could ever say "Me go for a bath now" I think I would never stop celebrating. I have to stop myself from laughing when one dad, in his sharp suit complains that his 5 year old son isn't interested in playing Scrabble according to the stated rules, but prefers to build towers with the letter tiles! Clever lad! It seems to me a much better way to approach the game.

About three weeks into the course we are asked to split into groups of 3 or 4 to discuss our child's "delayed" speech, and progress noticed recently within the group, hopefully to draw on the experience and advice of other parents in the group. I put my turn off until last, hoping to run out of time before the spotlight is turned on to my hopeless case. Alas, I can stall no longer and I admit, "She doesn't say anything" No body knows what to say. I look down, trying to think of something positive to say. "Well, how old is she though?" A group member is, I know going to try to explain it away by pointing out how young she is. "Almost 6" I admit. "Well she probably is saying more than you realise, is it that her speech is unclear?" "No", I admit, "She has never spoken." I fear I will regret this open admission later, but I feel numb at the moment, my feelings lie too deep for tears. An Asian lady wearing a sari and a black shawl smiles at me kindly and takes my hand "She sounds a special little girl, but maybe she will speak in her own way and in God's good time."

At the end of the 8-week course we are all presented with certificates, and give and receive polite applause. I have learned nothing from the presented course, but I feel I have made an important step forward. I have begun to look for strategies to help Daisy and me. I have begun to stop letting myself be dragged kicking and screaming through innumerable hospital departments, but have taken a step towards taking control. The course itself has been useless, but I feel I have somehow put the engine into gear. The Asian group-member's words are probably the most significant thing I take from the experience, and I let them rest in my mind. "In God's good time" she had said. Perhaps I should think about God's good time a bit more. Maybe Daisy is not concerned with the sort of time printed in those baby books of guilt so blithely handed out by the health visitors, and is working on a different plane and a different time altogether.

Chapter ?

One day, I receive a letter from my health visitor. The letter is unwelcome, too much to bear, too emotive, too direct. I am still hoping everything is going to be alright, that delay is just delay, although in my heart I know that this dream is slipping away from my grasp.

“Dear Rachel,

I have come across this piece of writing. I thought it was lovely and I hope you do too.

Yours etc.....”

I look at the enclosed piece of paper and, at the first sentence my eyes brim with tears. I scan the rest of the piece and hurriedly cast it to one side. I am about to screw the paper up and put it in the bin when something makes me change my mind. I carefully put both pieces of paper back into the envelope and slip them inside the chaos of a kitchen drawer. I can't deal with the message now, but perhaps the time is coming when I can.

Day by day, week by week, month by month, I read a little more of the prose. Little by little, year by year, I take a bit more of it in, think about it, learn its wisdom, accept it, embrace it, love it, pass it on to you.

Welcome to Holland

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. Its like this

When you're going to have a baby its like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. Its all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes in and says “Welcome to Holland!”

“Holland?!” You say. “What do you mean Holland? I signed up for Italy. I'm supposed to be in Italy! All my life I've dreamed of going to Italy” But there's been a change in flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting place full of pestilence, famine and disease, its just a different place.

So you must go and buy new guide books. And you will learn a whole new language. And you will meet a whole new group of people you never would have met.

Its just a different place. Its slower paced than Italy, less flashy than Italy. But after you have been there a while and you catch your breath. You look around you, and you begin to notice that Holland has tulips, Holland even has Rembrants.

But everyone you know is busy coming and going from Italy and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say "Yes, that's where I was supposed to go. That's what I had planned"

And the loss of that will never go away because the loss of that dream is a significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Emily Pearl

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Chapter 21

The difficulties sometimes come from unexpected places; what could be more fun, more normal and unremarkable, for a 6 year old, but an invitation to a birthday party? But as I get ready to take Daisy to the party, I begin to worry about the event. What about the children's games? Her dyspraxic, uncoordinated fingers will be able to take the paper off the pass-the-parcel. Will there be musical chairs? It will confuse her. Only just having mastered the skill of walking whilst an adult does the balancing for her, she will be unable to think and move quickly enough for the game. And so on and on. I rush to the bathroom and vomit. Can I get out of going? Can I fake an illness? Perhaps my vomiting is not due to nerves after all, but maybe I have a tummy upset, and I don't want to pass it on to all those children. Daisy looks up at me and grins. She holds out her arms to me. I pick her up and she snuggles in to my shoulder. I have to get a grip. It's not all about me. I have to steel myself and go to the party.

At first all goes well. I know the majority of the people at the party from church, but I stopped attending ages ago on advice from Dr Dodds, who worried about Daisy picking up illnesses dangerous to her because of her compromised immune system. I feel uneasy, on show and self-conscious.

The ordeal begins. The children have to sit at a table whilst the parents "relax" in another part of the room. I try to manipulate the situation by getting Daisy to sit at the end of the table nearest to where the adults are, so that I will be able to help her but notice, to my dismay, that the places have already been pre-determined.

Flustered, jolly-sweat-shirted facilitators buzz around the table serving the children with their party food. I feel sick again as I watch one particularly un-child-friendly lady serving each child with a drink. Jug in each hand, she asks the same, simple question of each child; "orange or blackcurrant?" She receives a reply from each child in turn, who is rewarded with the drink of its choice. She is getting nearer and nearer to Daisy. I watch from the other side of the room. What is going to happen? Daisy can't speak, how can she answer the question? She won't be able to drink out of the wobbly white plastic cups anyway without spilling it or knocking it over; she still drinks from cups with lids at home. If I were to admit that she couldn't speak I would choke on the words. I am frozen to the spot as I helplessly watch Daisy gaze

mutely at the red-clad stranger as she poses the simple question “Orange or blackcurrant?” She asks again. Still no response. It has obviously been a long, trying day for the facilitator. To my horror I see her eyes narrow as she raises her voice and snaps, “I said, do you want orange or blackcurrant?” It is too much for Daisy and I see her lip begin to tremble and quiver. I cannot reach her and, as she begins to cry, another of the facilitators has to lift her across the table to me. Whilst she clings around my neck, I cannot decide who is comforting whom.

Next up, ordeal by party games! As predicted, pass the parcel comes as the first trial. My heart is pounding and I feel I am in a state of red alert. Will I choose fight or flight? Daisy sits in the circle as the parcel draws ever closer. As the music stops, each layer of newspaper reveals a forfeit; sing a nursery rhyme, hop round the circle, do 5 star jumps. This is truly awful. I approach Daisy and, in a staged whisper, enquire, had we better visit the loo? Brilliant! That was close! I spend an unnecessarily long time changing Daisy’s nappy before returning to the playroom, where we stand on the sidelines, watching all the fun.

Chapter 22

Early one morning I hear the familiar soft thud of the day’s post plopping onto the doormat. Amongst the usual bore of bank statements and flyers from local takeaways is the welcome sight of a postcard. It is from friends whom we saw often before Daisy was born. Never having had children, their lives seem a world away from the world I now live in; pure, uncomplicated freedom. It was a world I lived in such a short time ago. The words of A E Housman expresses the feeling perfectly “That is the land of lost content, I see it shining plain, The happy highways where I went, And cannot come again” I read the card with a choking feeling of desperation and jealousy “Having a great time in Egypt, visited the pyramids yesterday – what an amazing experience. A relaxing day by the pool today.”

Back in my world it is a drizzly, damp November day. I think back to our holiday in Provence just before Daisy was born. They were the salad days, the dog days, the holiday days, the high, final days of apotheosis before the roller-coaster plunge.

What about the idea of nemesis? Not, perhaps divine payback for specific wrong doing, but more the idea of universal balance, balancing the books, justifying the margin. Until now we have been fortunate enough to enjoy a happy marriage, good times with our friends, meals out, weekends away. Perhaps you make the choice; have a great time, laugh all you like, enjoy the sunshine, the beer and skittles, but beware! You will sure enough pay for it later. Perhaps pay-back time is here? Perhaps the chickens have come home to roost?

Although it is not a Christian idea, it is one that is hinted at overtly and covertly by a couple of people at my church. One lady sits me down and tells me the story of a couple she knew whose chickens came home to roost; the man had an affair with a friend of his wife. When they were found out an acrimonious separation and divorce followed. The new couple had a child together a year or two later who had Downs. “I always felt it was a judgement on them, because what they had done was so wrong”

I think of poor Job in the old testament, grappling with the problem of his own terrible suffering, trying to understand it, trying to find a reason for it. The idea of Job's comforters has passed into our own everyday speech, for miserable comforters they certainly turned out to be, and yet the question is raised by others, as I raise it to myself, "Consider now, who, being innocent, has ever perished, Where were the upright ever destroyed? As I have observed, those who plough evil and those who sow trouble reap it" Perhaps, I muse gloomily, they may have had a point.

Chapter

One of Daisy's Early Years Teachers has a son, slightly younger than Daisy, who has Down's syndrome. She is a vivacious, energetic teacher in possession of the natural authority envied by most teachers. It is the first time she has met Daisy and she seeks me out after the session. "My own son has Downs," she tells me, "and I recognise some of the characteristics" What characteristics? I feel I am standing on the edge of a very deep chasm. I think it is the first time anyone has so matter-of-factly and openly acknowledged that Daisy's differences are real and apparent. It is terrifying, shocking and upsetting but, simultaneously, it is such a relief.

I find Jane's positive, pragmatic approach to her son's disability new, challenging and totally different to any other reaction I have experienced. She is streets ahead of me in terms of her acceptance of her son's situation. I suppose that her son's early diagnosis of Down's syndrome has given her the opportunity to mourn the child she thought she was going to have and she has grown to accept and love the one she finds herself with. Even so, my easy tears must seem pathetic to her. She invites Daisy and I over to tea and I am surprised to see Jane and her son Billy using sign language for all their interactions. Her manner seems firm to the point of brutality to me, demanding responses to questions about what he will choose; orange or blackcurrant? More toast? Enough? She holds her son's chubby little hands in her own and seeks eye contact. "Look at me Billy" "LOOK at me BILLY!" she commands. "Look at me. Orange or blackcurrant" If Billy doesn't use a sign, or if a sign is new to him, Jane demonstrates and then manipulates Billy's chubby fingers into submission. Daisy sits quietly beside me eating her marmite soldiers that I have requested for her, eyeing her teacher and her son suspiciously. Neither of us can believe what we are seeing.

Jane tells me about the rift that has widened between her husband and herself after Billy's birth and diagnosis. "He just went to pieces. He just sat with his head in his hands and cried and cried. But I have to do this, I have to cope, and if I have to cope on my own then I will do so." She takes a swig of tea. I feel a stab of pity for her husband being metaphorically dragged along by the hair by this formidable woman. "He will go to mainstream school like his older brother and he will be like everyone else. I am hoping he will drive a car when he is older" I think of my own low expectations in contrast to this lofty aim. All I usually want to do is to get as far as bedtime each day without killing myself or killing somebody else. I hadn't thought in terms of coping with driving lessons.

"I am booked onto a Portage course in a few weeks. I think you should come too" Portage is an educational programme pioneered in America aimed at teaching young

children with special needs. The approach is basically designed to work on the “area of proximal development” That is to identify the stage at which the child is currently, and to consolidate and extend that stage by tiny incremental steps.

I find the idea of attending such a course frightening. My initial reaction is to put my hands over my ears and scream “No, no, no. My child does not have special needs, she has developmental delay, and she will catch up!” But I swallow the response. It isn’t all about me. It has been up until now, but it has to stop. I don’t think Daisy has suffered by this, but she will do if I carry on. Jane’s frankness and fiercely pragmatic approach is inspirational and challenging. I’ll say yes. Why not.

I collect Jane on the four dark November mornings of the course and find her rushing to get ready, barking and signing instructions to Billy to finish his breakfast, tidy his toys, and wipe his nose. I am reminded forcefully of how different our approaches are. Jane leads, drags, and insists, from the front. Her expectations are sky high. She just doesn’t take no for an answer.

The course is useful and practical. It is led by two educational psychologists and attended, apart from me, by men and women in a professional capacity; paediatricians, nurses, speech therapists, and teachers. The course turns out to be a significant step for me; it changes the way I talk with Daisy and the demands that I place on her in terms of her responses and her behaviour. The course is all about clearly identifying the problem then clearly identifying the solution. It is about clarity and simplicity of thought and speech. It is about expectations.

Until now I have made Daisy’s breakfast and spooned it into her mouth, or I have made her a drink and held the cup to her lips. What else can I do? She can’t talk and she can’t manipulate a spoon between dish and mouth without spilling the contents all over herself and the floor. She can point though. I cut out the distinctive, colourful label from a cereal packet and take the label from a jar of marmite, and stick them at Daisy height on the fridge door. I know its not breakfast time, but lets try it out anyway. I show Daisy the labels and say the words. “Daisy, look. Sugar puffs.” I point to the label on the fridge door. “Daisy, look. Marmite” Daisy looks from one label to the other and then back at me. She looks at me for a long time with her beautiful, vacant green eyes. What a waste of time that was. Then to my utter astonishment Daisy turns and stabs at the picture of the sugar puffs honey monster grinning out from the fridge door. “Eureka! She has made and communicated a clear choice. Daisy is communicating! I think of the educationalist Harry Chasty’s wise advice; “If a child doesn’t learn the way you teach, teach him the way he learns” I feel 10 feet tall. Daisy and I sit on the kitchen floor in companionable silence, each with our bowl of dry sugar puffs, smiling at each other as we pop them, one by one into our mouths. No mother of a capped and gowned PhD graduate could possibly feel prouder.

Trying to apply the lessons learned on the portage course, I try to see the world as much as I can through Daisy’s eyes. Daisy’s life will become so much more rich and interesting if she can make choices. So far I have done absolutely everything for her. I choose what she eats and drinks, where she goes, what she wears, what her bedroom

looks like. Now, as far as possible, Daisy will choose. I don't just read her a story, I offer two books, and she points to the one she would like to hear. I don't just dress her, I show her two possible outfits, and I wait as she chooses the one she prefers, by pointing. If she chooses spots to go with stripes, ok. If she chooses purple to go with orange, so be it. I buy mirrors and hang some on the wall so that Daisy can see herself if she is standing, and some on the wall so that she can see herself if she is crawling.

But what about communication? Words and language have always been my love and my inspiration. English was always my strength academically all the way through school and college. I love poetry and literature and marvel at the way all the poetry, all the novels I have loved, all Shakespeare's plays and sonnets are comprised of just 26 letters, which make up our alphabet. There is not a sentiment or a feeling that cannot, with the right choice of words, be captured and expressed. If a spiteful God was to take away one thing to really hurt, for me, it would be language, spoken, written. To deny me the pleasure of watching a similar skill and love develop and grow in my own child, to keep from me the joy of teaching my child to read, would be to cruelly exploit my Achilles heel.

I was angered and upset by what I saw as a cruel attack by Daisy's teacher Jane one day. "Why don't you sign with Daisy? She is 6 years old and she is still not talking. How do you communicate with her? You don't do you?" I don't have an answer. The truth is I have continued to communicate with her as any mother communicates with her baby. Daisy and I have spent days and nights together over months and years. I suppose we just think we know what each other mean. We have never moved on from that very basic level of communication. After all, isn't about 80 % of human communication supposed to be non-verbal? (Although it doesn't really work on radio.) But with no words, how can she ever tell me about her world? Tell me what she feels? Tell me about herself? And how can I tell her about my world? I have learned her language, but she has not learned mine, never can if there is no speech. Signing would, perhaps allow us to meet somewhere in the middle.

I have been attending weekly speech therapy sessions since Daisy was about 2 years old, but I have to say I have not found them to be much use; the sole approach of the innumerable therapists I have seen has been to record endless assessment carried out on Daisy, then do a few sessions about turn-taking when playing, then to either go off work on long-term sick leave, or to refer us to someone else. Maybe Jane does have a point. Instead of bemoaning the shortcomings of the speech therapy service, perhaps it is time to take matters into my own hands. I have been amazed and impressed by the experience of watching Jane and Billy signing together. I buy a simple signing manual, the Dave Benson Nursery Rhyme signing video and get going. To my huge amazement and pride it only takes a week or so before Daisy is clearly and confidently and eloquently signing "more" This simple sign opens up a whole world of possibilities for Daisy and me; It can be "more" anything, More singing, more stories, more to eat, more to drink, more this, that or the other. It is the beginning of purposeful two-way communication, and it feels that a door has been opened for us.

Chapter 23

It is the occasion of a friend's wedding, and Daisy is staying overnight at her grandparents for the very first time so that we can attend the evening reception. I feel so free, so light and unencumbered. Just getting out of the car without Daisy seems such a treat; I simply get out of the car, close the door and walk away. Weddings are such grand occasions, such a feeling of love and happy expectation of years of sharing and togetherness. Everyone is laughing as the band plays and we swirl around the floor to "Daisy, Daisy....." I am beginning to feel happy and proud of my own Daisy.

Chapter 24

One Sunny day in May I am listening to my CD of Mendelssohn's Oratorio "Elijah" I listen to the music over and over, and I feel a special resonance with the words and music. I pause to listen to the familiar words again as I drag the day's wet washing from the machine.

"Night falleth around me, O Lord, A misty wind rent the mountains around and brake in pieces the rocks, the sea was upheaved and the earth was shaken, and after the earthquake came a fire, and after the fire there came a still small voice, and in that still small voice, onward came the Lord..... And in that still voice, onward came the Lord."

If only it were that simple. If only I could hear that still voice. Crouching over the washing basket, I lean against the washing machine and close my eyes. "Help Lord, Wilt thou quite destroy us? You said the burden would be light. Please send someone or something to help me"

Daisy, after a restless, sleepless, feverish night, is now sleeping peacefully on the sofa in the living room. I tuck the fleece blanket around her and kiss her brow. Her fever has cooled and I think she is on the road, once again, to recovery.

I walk down the garden in the spring sunshine to the washing line with the heavy laundry basket. As I am pegging out the sheets, I hear the sound of footsteps on the gravel and look up. I see the unfamiliar black face of a stranger. I leave the washing basket on the grass and approach her. Apparently she is lost, and seeking directions. She tells me she is from London, is house hunting and has been driving around for more than four hours! I invite the weary traveller in and, later that morning, sitting at our kitchen table drinking our umpteenth cup of tea, I hear Rose's story. She has recently taken up a post at the university, researching children's experience of grieving and bereavement. Her husband works for the church and both are involved with running groups for adults with learning difficulties.

"I feel that these people are so special" She tells me. "I think that many are destined for special things in the world to come, and so that is why God has made them special in this life, to keep them untainted, innocent, precious." I feel my eyes swim with

salty tears. “What a privilege for you and your family to be chosen to care for Daisy in your lifetime. You have God’s blessing “

A new idea, a fresh slant. To see Daisy not as a curse, or a burden, or a trial, but a blessing. To feel chosen for a special task. What a responsibility, but what a breathtaking honour. What a privilege. All the people God has singled out for special, difficult jobs have also been given the necessary, special help them to deal with their task.

I feel stilled like Elijah. I have shouted in the storm, clung to my life in the earthquake, been scorched by the fire, thinking God was in all these things, but he wasn’t, but at last I think I heard him in the still small voice of lovely Rose, who appeared like an angel on that warm spring day, and whom I never saw again.

I check Daisy again and find her still sleeping under her blanket, her arm around her faithful teddy bear, Chester. I sit in the garden under the flowering cherry tree, drinking in its heady scent and think over and over the words that Rose has spoken. Tears come like a river, but they are not tears of grief, or anger or even sadness, but tears of relief and of something beginning to be understood.

Within the ageing pages of a tatty recipe book, I have a poem written on a yellowing piece of paper apparently according to the fading inscription, given to my maternal grandmother by a neighbour over 60 years ago. How it came to be in my possession I cannot recall, but I think about the poem after Rose has gone, and search for it. Here it lies in my hand, as it once lay in tm grandma’s, hopefully encouraging her then through a difficult situation, long ago forgotten and never known to me, as it encourages me now:

Lean Hard

Cast thy burden upon the Lord, and He shall sustain thee. (Psalm 55:22)

Child of my love, lean hard,
 And let me feel the pressure of thy care;
 I know thy burden, child. I shaped it;
 Poised it in mine own hand; made no proportion
 In its weight to thine unaided strength,
 For even as I laid it on, I said
 “I shall be near, and while she leans on Me,
 This burden shall be Mine, not hers;
 So shall I keep My child within the circling arms
 Of my own love.” Here lay it down, nor fear
 To impose it on a shoulder which upholds
 The government of worlds.
 Yet closer come:
 Thou art not near enough. I would
 Embrace thy care;
 So I might feel My child reposing on My breast.
 Thou lovest Me? I knew it. Doubt not then;
 But loving Me,

Lean hard.

(Author unknown)

Like the biblical figure of Jonah, I have felt angry, sulky, abandoned by God. I have been through years of blasphemously denying his very existence. Quite simply I didn't understand the task, didn't want the task, and didn't want to carry out the immense, unfathomable task I have been given. But God patiently waits. Apparently sometimes he doesn't take no for an answer. I think God saw how I went to pieces when the provisional diagnosis of Downs's syndrome was given, and that situation, that trial was withdrawn for a time, but it had to be gently but firmly handed back. Daisy, for reasons I still do not understand, had to be different, had to be special. Is it for my ultimate benefit, or hers, or someone else's? I don't know, but what I do now know for sure is that Daisy has taught me more, much more than I have ever, or will ever, teach her. Important things. Eternal things.

I think of Offenbach's lyric again. "when you can't have what you love, you must love what you have" What a journey! How far I have walked and how much I have been blessed to learn. I not only love what I have, but at last, I have what I love, and much more besides.

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Epilogue

I grew up in a Christian family and went to Sunday school every week. I have attended thousands of Christian services and bible study groups. I was baptised when I was 18 in 1982, but it was not until 20 years later that I was converted.

In her early years Daisy was dangerously ill several times and she has severe learning difficulties and various health problems.

I used to wonder why God could allow Daisy to have been born like this and I used to anticipate the future with true dread, but now I have come to think very differently.

When I look back over the circumstances of my life I can see that God has very skilfully arranged every detail to equip me to help and to care for and to love this very special person. I have come to trust that God has a special plan and a reason for making Daisy the way she is. For instance, my early life gave me lots of opportunities for learning patience and flexibility. My working life gave me useful connections with the local hospital . I was even guided into taking a degree course on teaching children with special educational needs before Daisy was even born. I was encouraged to take another degree in educational psychology before Daisy's problems were fully known by me.

I was taken to a specific place where the school which Daisy attends is like a happy family; far superior and better suited to Daisy's needs than any other school I have knowledge of.

I have come to know wonderful people who have helped and supported me.

Although in my faithlessness I worry, I know in my heart that I have no need to fear the future. God has guided me in the past with such precision; always sent help via exactly the right person at exactly the right time. I have no reason to suppose that things will be any different in the future. I know I will be sent the strength and the patience to deal with whatever the future brings.

I still do not know why God thought it necessary for Daisy to be how she is, or why he chose me to be her mum, but I feel honoured that He did. If you know Daisy you will know what a joy and a blessing she is.

My favourite person in the bible is Mary, the mother of Jesus, who said “yes” to the enormous task of being mother to the son of God himself, giving no thought to the huge implications this had for herself. My favourite verse in the bible are her recorded words in Luke 1 verse 38 “Be it unto me according to Thy word.” What an example! Life becomes so much more simple, so much more blessed if we can only try to copy that attitude little by little, each day.

